

KINKED AND CRIPPLED: DISABLED BDSM
PRACTITIONERS' EXPERIENCES AND EMBODIMENTS
OF PAIN

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Abstract

The thesis explores the experience of pain for people who live with chronic pain and engage in BDSM¹ (or 'kinky') pain play. It is situated within disability studies, taking the position that chronic pain is a disability, and in the use of crip theory to explore narratives of experience. The narratives, told through multiple, detailed interviews were explored in the contexts of crip theory, disability, and medical and social understandings of pain.

The thesis addresses three core aims; firstly, to hear narratives of experiences of chronic pain and BDSM play. Secondly, to explore those narratives to reveal experiences and understandings of pain sought by those who live with chronic pain and also engage in BDSM. Finally, to challenge normative conceptions of pain through a critical crip reading of the narratives. The narratives revealed a range of complex experiences. I drew out these narratives in three broad themes: the role of crip time in living with chronic pain; the multiple uses of BDSM – including pleasure and control of the self – and the role of stigma and abjection.

¹ BDSM stands for bondage and discipline, dominance and submission, sadism and masochism (Bauer, 2014; Langdrige and Barker, 2007; Taylor and Ussher, 2001).

The thesis has made a number of original contributions to knowledge. Firstly, it revealed how pain is discursively constructed as needing control and containment, but how non-normative methods of control and bodily engagement are not necessarily understood as such. Secondly, the thesis exposes how pain is assumed to be wholly destructive to the self, but instead ways to integrate pain into the self are sought. Thirdly, it adds to crip theory by expanding the notion of crip time to reflect the experience of living with chronic pain. Finally, by demonstrating how the narratives challenge understandings of the 'normal,' as reflected in discourses of chronic pain. The thesis thus exposes how normative constructions of pain are a part of the performance and construction of able-bodied minded heterosexuality.

Keywords

Pain; crip theory; disability; BDSM, control, normativity; crip time; stigma; abjection.

Dedication

For Arthur Gill, my grandfather.

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Introduction

This thesis explores the narratives of pain as told by people who live with chronic pain and engage with painful play in BDSM. It pulls theoretical understandings and knowledges from a range of disciplines and areas, with a particular focus on crip theory, disability, abjections, and understandings of pain as both social fact and somatic experience.

The Research Aims

This thesis sets out to answer the following three questions:

- A. What narratives are told by people who live with chronic pain and engage in painful BDSM play?
- B. What do these narratives say about their experience and understanding of pain?
- C. How can a critically crip reading of these narratives challenge normative conceptions of chronic pain and thus further the inclusion of pain within crip theory?

The research, while taking inspiration and knowledges from a wide range of disciplines, and owing much to the work of disability scholars, is working within the spaces of several established understandings. However, none of these established understandings currently approach chronic pain from a disability standpoint at the same time as approaching BDSM and pain, and a crip approach gives the space to destabilise and build on these understandings.

In taking pain as something that is both felt and discursively controlled, it is perhaps possible to understand it as something more than injury or the cause of a disrupted life; if we look at the ways pain *constructs* rather than destroys, how it is sought and lived with rather than rejected and feared, we can perhaps begin to deconstruct that exclusively negative discourse, to posit pain as not ontologically impossible, and to not invalidate the lives of those who live with pain. For this, it is necessary to explore pain, as a phenomenological experience, from the viewpoint of disabled people who live with chronic pain as a part of, or all of, their impairment. Examining any experience from a disabled point of view “exposes with great force the constraints imposed on bodies by social codes and norms” (Siebers, 2006, p. 174); examining pain will expose the normalisation of how pain is experienced – or perhaps more accurately, how varying discourses tell us pain *should* be experienced. Coming from a critically crip approach, which combines a critically disabled position and a critically queer position

(Kafer, 2013; McRuer, 2006), it may be possible to *crip pain*, rather than merely queery the construction of pain as impairment – exposing how normative constructions of pain are a part of the performance of able-bodyminded heterosexuality.

Normative understandings of pain, informed by medical knowledge, do not adequately cover experiences of chronic pain, or pain in BDSM play. At the same time, crip and disability theories have only begun to address pain – chronic or otherwise. Pain is thus under-theorised in both contexts, and there is a need to bring crip theory to bear on experiences of pain in order to challenge normative understandings, in order to further inform chronic pain as disability, and conceptions of bodies within crip theory. In addition, the understanding of pain in disability and BDSM is – at least at first look – very different, and located in experiences that are assumed to be exclusive. There are no studies which explore pain in both situations, especially not from the viewpoint of those who experience pain both as people engaging in BDSM and through living with chronic pain.

Facts and Figures

In terms of how many people live with chronic pain, Richardson's 2005 paper collected estimates of the prevalence of chronic widespread pain (which is defined as existing in more than one location in the body); those estimates range from 4.7% to 11.2% of the population of Australia (ibid. 2005). Conrad and Munoz, in 2010, gave conservative estimates between 2% and 10% of adults in American, stating that other estimates went as high as 33% (ibid 2010). Figures in the UK range from 11% to 16% (British Pain Society, 2008; Baker *et al.*, 2010; Price *et al.*, 2012), with an estimate for the EU as whole giving a figure of 20% (Baker *et al.*, 2010). Fayaz *et al.*'s (2016) meta-study of published articles gave higher figures, of 35% to 51.3% of the UK population, although the "prevalence of moderate to severely disabling chronic pain was lower and ranged from 10.4% to 14.3%" (Fayaz *et al.*, 2016, p. 1); the participants involved in this research would fall into this latter grouping.

Incidence of chronic pain (or at least chronic pain reporting) is higher in women (Bendelow, 1993; Bury, 1991; Baker *et al.*, 2010; Fayaz *et al.*, 2016; Hoffman and Tarzian, 2001; Nielsen and Fernandez, 2010); in most studies of pain reporting since the 1970s, "women reported more severe levels of pain, more frequent pain, and pain of longer duration than men ... women were also more likely than men to develop a chronic pain syndrome after experiencing trauma similar to that of men." (Hoffman

and Tarzian, 2001, pp. 13–14). However, when it comes to gender, this statement does not include intersex, non-binary, trans, or agender individuals – and I could not find statistical data estimating the incidence of chronic pain among non-cisgender populations.

Beyond gender, Fayez *et al* reported that there is a trend towards incidence of chronic pain increasing with age; their figures for adults over 75 years of age were 62%, falling to 14.3% in young adults aged between 18 and 25 (Fayaz *et al.*, 2016). UK-based studies have reported a higher incidence of chronic pain in non-white populations (Nicholl *et al.*, 2015); this is echoed in US-based studies (Hoffman *et al.*, 2016; Trawalter *et al.*, 2014). Other studies have reported a relationship between lower incomes or education levels and chronic pain – in that those with lower incomes and education levels are more likely to experience chronic pain (Nicholl *et al.*, 2015). However, these studies did not differentiate between types of chronic pain, the severity of impact on the lives of those with pain, or the diagnosis they were given.

When it comes to intentional pain and sex, the numbers of people who engage in BDSM vary depending on what behaviours or activities are being defined as BDSM. Broad surveys of sexual behaviour in the United States gave figures of 5% to 14% of

adults engage in BDSM (Bauer, 2014; Janus and Janus, 1994; Reinisch, 1990), while Kolmes *et al*'s figures go as high as 50% (Bauer, 2014; Kolmes *et al.*, 2006). While all these figures are for the United States, it is not inconceivable that similar figures would be found in the UK – or that people living with chronic pain could also be engaging in BDSM play. However, there are no figures for the overlap.

Originality

The thesis has made a number of original contributions to knowledge, organised in three themes: crip time, control, and abjection. In the first theme, the thesis adds to crip theory by expanding the notion of crip time to reflect the experience of living with chronic pain, including phenomenological and embodied experiences alongside experiences of 'slowness.' Through widening the notion of crip time, it is possible to explore a wider range of disability experiences, particularly experiences of bodily difference and limitation.

In the second theme, control, the thesis reveals how pain is discursively constructed as needing control and containment, but how non-normative methods of control and bodily engagement are not necessarily understood as such. This impacts conceptions

of self-control, and troubles notions of how control should be performed. This ties in with the third theme of abjection, in which the thesis demonstrates how the narratives challenge understandings of the 'normal,' as reflected in socio-cultural and medicalised discourses of chronic pain. The thesis thus exposes how normative constructions of pain are a part of the performance and construction of able-bodied minded heterosexuality, and how individuals with chronic pain are pushed to perform self-abjection and normative pain control practices, while their non-normative practices and experiences are ignored.

Scope and Boundaries

The research is not intended to offer a medical solution to pain, although I hope it will contribute to destabilising medicine's understandings of pain. In addition, while I hope it will contribute to a change in the lives of people living with chronic pain, it is not intended as a guide to doing so – rather a contribution to an understanding of disabled bodyminds that is rooted in a need for change in current social systems.

I have gone for depth, rather than breadth, as it were – and spoken to a small number of participants to produce detailed narratives. Thus, while I have analysed their

narratives both individually and as eight parallel narratives, I have not attempted to ensure the participants were a representative sample of any particular population,² and their words should not be taken as such. Thus, while some aspects of their narratives could be generalised - or at least have parallels drawn between them – I would not encourage the reader to assume that the experiences will be shared by those not included here.

The participants all lived in the United Kingdom, and thus their experiences of medical care were shaped by the National Health Service – and its myriad idiosyncrasies – and the UK's social care and welfare systems, which were, at the time of the fieldwork (2014 – 2016) undergoing a period of cuts, upheaval, and change. I have not sought to analyse participants' narratives in terms of class, but it should nonetheless be noted that while several of the participants had a middle-class childhood, it would be difficult to justify identifying them as middle-class at the time of the research, given that six of the eight were unemployed and surviving on state welfare support (of the remaining two, one was in well-paid employment, and the other was in poorly-paid precarious employment; both received in-work state support). Any misrepresentations of their experiences are entirely my own fault.

² See *Facts and Figures* on p.15

The narratives of people of colour living with chronic pain are missing from this thesis. The narratives of people with learning disabilities and those who communicate non-verbally are also missing.

When it comes to BDSM practices, I do not seek to condemn or add to the pathologisation of BDSM practitioners; I have heard those narratives that include self-harm and 'risky' edge play and analysed them, but instead take the approach that BDSM players engage in their individual preferences with the approach of *risk-aware consent* – that is, they do so being aware of their own limits, capabilities, and preferences, and it is not for others to judge them negatively for doing so.

Key Definitions and Language

Before the main part of the thesis begins, I want to set out the language used in the thesis, and my reasons for doing so. The language choices I have made reflect my own personal political leanings, as well as my sociocultural positioning as a disabled woman in the UK. I have made decisions around several particular words and phrases: *'disabled person,' 'disability,' 'impairment,' 'body and mind,'* and *'chronic pain.'*

I use the phrase '*disabled person*' over '*person with a disability*' for multiple reasons. Firstly, I am in the UK and this is the preferred phrasing of disabled people in the UK. Secondly, it reflects an understanding of disability rooted in the social model, in that disability is imposed upon bodyminds (see below), through ableism, rather than an inherent property of certain bodymind; disability is social, not individual. Finally, it is the phrasing I prefer to use for myself. I have used the phrase '*able-bodyminded*' to refer to the ideal; individuals are '*non-disabled people*.'

The exception to this is in referring specifically to '*people with learning disabilities*' – because this is the preferred phrase of their community in the UK. Thus, the phrase '*disabled people*' refers to all disabled people, no matter the 'category' of their disability or diagnosis; I have only differentiated where necessary.

I have not taken the social model approach of separating disability into '*disability*' and '*impairment*' – into the process of disablement, and the medical diagnosis – because, having taken a crip theory approach, I feel it is somewhat inappropriate to do so, given the difficulty the social model has with acknowledging pain, fatigue, and other negative sensations or capacities (Hughes and Paterson, 1997; Kafer, 2013; Rembis,

2010; Siebers, 2006). In addition, impairment as a category relies heavily on medical diagnosis, and I wish to move away from the restrictions this places upon how bodies are perceived of. Thus, unless I am referring specifically to impairment within a social model understanding – or quoted from another’s writing – the term ‘*disability*’ has been used.

The binary division of ‘*body and mind*’ is inappropriate in considering pain, and reinforces the separation of people with learning disabilities from disabled people as a whole; thus, I sought to find a term which works against both divisions. I have taken the word ‘*bodymind*’ from Price (2015), who explained her use thus: “because mental and physical processes not only affect each other but also give rise to each other—that is, because they tend to act as one, even though they are conventionally understood as two—it makes more sense to refer to them together, in a single term. I started using *bodymind* freely, mostly because I was tired of saying *body-and-mind* all the time, and unhappy about the implicit division created by the coordinating conjunction.” (Price, 2015, p. 269). For myself, frustrated by the limitations of ‘*able-bodiedness*’ (which can be easily read as excluding cognitive and learning disabilities), and the clunkiness of ‘*able-bodied and able-mindedness*,’ which reinforces the binary of bodily and mental disabilities; I wanted a phrase that included without dividing.

Within the research, I focus on chronic pain as an experience, rather than as a medical diagnostic category in itself; some disabled people experience chronic pain as a part of their disability, for a wide variety of reasons, while other disabled people experience chronic pain as their disability. I felt at the outset that limiting the research to a particular form or cause of chronic pain would place pain firmly in a medicalised setting, as well as limit the range of possible participants. I would perhaps define chronic pain, from my own experience, as pain that has lasted or recurred over a sufficient period of time that the person experiencing that pain feels it has moved beyond an immediate experience into a long-term one, which they may define as ‘ongoing’ or ‘abnormal,’ with little or no practical prospect of cessation.

Throughout the thesis I use the phrase *people ‘living with chronic pain’* (or *‘person who lives with chronic pain’*); this is a deliberate choice. As a person who lives with chronic pain myself, I feel that *‘living with’* is a better descriptive choice than *‘having’* or *‘in’* chronic pain – in that while chronic pain has a massive impact on my own self-perception and my everyday lived experience, it is not the sum total of that experience; *‘having’* and *‘in’* leave less room for these nuances. It is also a deliberate rejection of the phrase *‘chronic pain sufferer’* – a phrase I particularly loathe, which erases all other aspects of my life and implies that a chronic pain cannot be lived with.

I have also used the first person / throughout. Trying to extract myself from the thesis, and maintain a place of aloof 'objectivity' would have betrayed my feminist and emancipatory research principles, and denied the interactive and deeply personal nature of doing this research, which I have detailed below, as well as in the conclusion. I reject the notion that objectivity is possible, let alone desirable. On top of that, I like the sound of my own voice.

A Personal Story

This thesis, and the research project, came about from a number of intersecting events – some personal, some less so. I would like to address those events chronologically, although the circumstances themselves were a little less neat. Firstly: I became disabled somewhere between 2002 and 2009; I cannot give you an exact date because disability crept up on me and by the time I knew something was different, it had been different for a while. In 2006, I was formally diagnosed with depression and anxiety. I was formally diagnosed with fibromyalgia in 2009. Becoming disabled with fibromyalgia changed my life a great deal, and it changed who I was, and who I was becoming. Recognising myself as a disabled person, identifying as disabled, was a slow process, but my disabilities are a part of *who I am*, and how I relate to the world.

Secondly: I used to work in a sex shop. I always hasten to tell people that it was a *nice* sex shop, with lovely friendly not-creepy customers, and I had taken my mother in there for tea and cake. These things are true, but also I paid the bills by selling sex toys and pornography to people. Two things came up³ in those six months: firstly, inquiries as to whether the shop stocked disability porn. Secondly: disabled people asking for advice – from ‘is this lubricant safe for sensitive skin?’ to ‘where’s a good wheelchair-accessible sex club?’ Disability porn was one of many niche interests the shop’s customers came looking for, and was rather difficult to find. The latter was more interesting, and after looking around and finding a small – but thorough – amount of advice for disabled people in heterosexual relationships wishing to insert tab A into slot B in a mutually-gratifying manner, I realised there was not much around that discussed sex – or sexuality – more broadly, more queerly.

At the same time as the aforementioned job selling sex toys, I was completing a masters in gender and sexuality; there was not much there about disability either. As a result of these spaces without disability, for my dissertation, I interviewed and wrote about three queer disabled people, about how acquiring their disability affected how

³ Stop snickering at the back.

they perceived of themselves as sexual people – and as queer people. One of the things that came up was pain, and BDSM – enjoying BDSM, and playing with pain, being queer kinky crips. And I didn't know what to do with this; I struggled to find resources.

Thus, we come to the fourth event: as a disabled person living with chronic pain, who was familiar with BDSM, I was reading about something new, and I wanted to know more, and I wanted to see how it fit in to theory. A lot of what I read about pain did not make sense to me, didn't chime with my own experience – and so the research project was born. A lot of my first reactions to what was read were gut reactions; I compared it to how I felt, what I knew – did it feel right? This is what produced my insistence on thinking in terms of acute and chronic pain, on separating them into two distinct, if broad, experiences. It was also what led to my methodology – which I have written more about at the end of the concluding chapter.⁴ This thesis is personal, and I have not sought to make it less so; to do so would deny its importance to me.

⁴ See p.346.

Thesis Contents

The first three chapters make up the literature review section; the first chapter provides the frame through which the literature on sex and pain is presented. Rather than individual conclusions at the end of each chapter, a summary conclusion is provided at the end of chapter three in order to draw together the key themes. The fourth chapter lays out the methodology, and chapters five, six, and seven make up the analysis. Constrained by convention to produce a linear account, I have attempted to indicate where crossing points can be drawn between various sections within the footnotes.

Chapter One: Disability

After laying out the UN definition (for the sake of completion), this chapter explores multiple meanings of disability. Beginning with the medical and individual models, after accounting the issues with this model, it moves into the social model and its limitations, and then into crip theory. At this point several important concepts are covered; the normal, stigma and abjection, and the role of neoliberalism in disability. Finally, the chapter gives a brief account of crip time, and some of the problems with crip theory.

Chapter Two: Pain

The second chapter attempts an overview of pain, firstly in terms of how it is understood, and then in terms of how it is perceived from a medical standpoint, and then a disability theory standpoint. There is a great deal of overlap with disability, and the chapter returns to conceptions of the normal and neoliberalism by exploring rehabilitation and control of the body, then curing pain. It ends with a very short overview of the notion of suffering.

Chapter Three: Sex

This third chapter explores sex in the context of disability, and then in the context of pain. Some consideration is given to situations in which pain during sex is normalised (virginity loss, and sexual violence), and then situations in which sex is a source of pain, or a painful experience – both of which are read as abnormal. Finally, the chapter turns to BDSM, and the position of pain within BDSM.

A summary of the main concepts and ideas from the literature is at the end of this chapter.

Chapter Four: Methodology

This chapter presents an explanation of the research methods – interviews and diaries – as well as the justifications, and ethical reasoning behind the methods.

Chapter Five: Crip Time

This chapter presents the first of the three analytical themes. It expands the notion of crip time to include the instability of being unrecognised as disabled, the time to self-identify as disabled, and to become accepting of one's disability and the changes to the bodymind – which I refer to as time to become crip. For people living with chronic pain, this includes crip time to integrate chronic pain into one's sense of self. My expansion of the concept of crip time also includes the experience brain fog and thinking slowly, and of living at a slower pace, particularly in terms of pacing. This is tied to the notion of control.

Chapter Six: Control

This chapter is the second of the three analytical themes, and demonstrates a complex relationship between chronic pain, BDSM, and different notions of control, revealed by the narratives of participants. The normative discourses control of emotional response to chronic pain is challenged by narratives of BDSM, and of negotiating care. BDSM also served as a way to make pain, and to control the

bodymind and sensation, as well as to forgo control – and to control pain directly. The narratives of control are closely tied to narratives of abjection, found in Chapter Seven.

Chapter Seven: Abjection, Analgesic Culture, and Crippling Pain

Chapter Seven presents the final analytical theme, the notion of abjection, as related to crip. The chapter explores how chronic pain is made abject, and demonstrates how participants felt pushed to perform self-abjection, to publically and privately reject their pain. This is tied to the notion of analgesic culture within neoliberal rehabilitation regimes, and how participants experienced and negotiated complicated relationships with diagnosis and medical care. Through crippling pain, this chapter explores how participants responded to chronic pain *through pain*, particularly BDSM. The chapter ends with a discussion of the unexpected ways in which narratives of being autistic emerged from several interviews.

Chapter Eight: Conclusions.

This chapter largely does what it says on the tin. It relates the conclusions found at the end of the previous three chapters to the original research aims, and then presents several ways in which the research could be built on. Finally, I reflect on the personal impact of doing the research.

Publications

Sheppard, Emma, 2016. Review: Supporting disabled people with their sexual lives: a clear guide for health and social care professionals. *Disability and Society*

Sheppard, Emma, 2015. Review: The Female Suffering Body: Illness and Disability in Modern Arabic Literature. *Disability and Society*, 30.10, pp.1593-1595.

Sheppard, Emma, [forthcoming]. "Researching sex and sexuality with disabled people". In: Claes, T., Porrovecchio, A., Reynolds, P. (eds) *Methodological and Ethical Issues in Sex and Sexuality Research: Contemporary Essays*, Barbara Budrich Publishers, Leverkusen.

Sheppard, Emma, 2014. Review: Feminist, Queer, Crip, by Alison Kafer. *Journal of the International Network for Sexual Ethics & Politics*, 1.2

Conferences & Seminars

Pain as Emotional Experience, January 2017, Disability and the Emotions Seminar Series, Centre for Culture and Disability Studies, Liverpool Hope University

Kinked and Crippled: chronic pain and BDSM, September 2016, Lancaster Disability Studies Conference, Lancaster University

Crippling Pain [poster], July 2016, Encountering Pain, University College London

The Problem of Chronic Pain, December 2015, Re-engaging Elaine Scarry's *The Body in Pain: A Thirtieth Anniversary Retrospective*, University of Brighton

And the cripp ran away with the spoon: cripp time, fatigue, and a life lived more slowly, April 2015, Cutting Edge 2015, Edge Hill University

Feel the Pain: the unexpected side effects of research, April 2015, Talking Bodies 2015, Chester University

Disability, Pain and the Normal Human, December 2014, Seminar, Edge Hill University

Crippling Pain: examining pain in normal human experience, July 2014, 5th Annual International Conference: Theorising Normalcy and the Mundane - More Questions of the Human, University of Sheffield

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Chapter One: Disability

I have started with disability as thinking through disability underpins the chapters on pain⁵ and sex.⁶ Disability is about more than lack, about more than illness or limitation; the crip concept of the normal human is a useful tool for unpicking and unpacking the constructions of both pain and sex. As the literature reviewed in these three chapters is drawn from a range of disciplines, and were not necessarily originally written with crip in mind, starting with disability provides the frame in which that literature was read. Rather than presenting conclusions of each of this chapter and chapter two, I have instead drawn together the key themes at the end of chapter three⁷ which draws together the key themes in ways that emphasise the links between the three topic areas of disability, pain, and sex.

Definitions and understandings of disability vary hugely, and, as Wendell writes, “arise in countless practical situations, influence social policies, and determine outcomes

⁵ See p.79.

⁶ See p.132.

⁷ See p.174.

that profoundly affect the lives of people with disabilities” (Wendell, 1996, p. 11).

These understandings of disability, although they construct disability in different ways, are all social constructs, which affect how people see and react to disability, as well as how disabled people see themselves. While these understandings might be ascribed to individual people as though they have been actively decided upon, they are not necessarily part of a conscious thought process. As social constructions, they affect diverse practical situations, from the construction of the built environment, to the provision of healthcare, and everyday social interaction. These definitions and understandings contained within the social constructions of disability also underlie the legal standing of disabled people, and affect their entitlements to state assistance – or lack thereof. In the UK, as in many countries in the global North,⁸ medical diagnosis – itself dependent on medicine recognising a set of symptoms as a particular impairment/disease - acts as gatekeeper to state support and state-controlled support systems.

Socio-cultural understandings of disability affect the identities of disabled people, including their ability and *willingness* to self-identify as disabled, and to see disability as a positive self-identification. Disability, as this chapter explores, includes a huge

⁸ The countries of Western Europe (including the UK), Canada, the USA, Australia, and New Zealand; those regarded as wealthy Western and capitalist nations.

range of impairments, symptoms, differences, and diagnoses, and the definition and identification of disability is made more complex as a result. To add to this complexity, some disabled people do not always identify as disabled for fear of being associated with another marginalised and disadvantaged group of disabled people. Other impairment- or diagnostic-specific groups may identify positively within their own group, as in the case of Deaf culture which can be considered as “distinct linguistic and cultural minority, more akin to Spanish speakers in a predominantly English-language country than to people in wheelchairs or people who are blind” (Kafer, 2013, p. 75); not all D/deaf⁹ or hearing-impaired individuals wish to identify as disabled, or ally themselves with a politicised disabled identity.

The breadth of differences¹⁰ included within understandings of disability is often obscured by the discourses within a culture that presents what Wendell (1996) refers

⁹ ‘Deaf’ with a capital ‘d’ indicates the cultural and linguistic minority identity, while ‘deaf’ with a lowercase ‘d’ indicates the impairment, the noun. A hearing child of Deaf adults may be considered part of the Deaf community, despite not being deaf themselves; being deaf does not automatically make a person Deaf, however.

¹⁰ See p.20 for more on language choices. I have used ‘difference’ here to indicate that disability can be understood as a difference from the expected, or the ‘normal’ – but would stress that not all difference is marked as a disability.

to as a 'paradigmatic disabled person;' the assumption that in order to be disabled one must fit into a relatively narrow category, and that once one is disabled through one aspect of bodily or mental impairment, one must also be impaired in other ways, that one is globally disabled.¹¹ It should also be noted that there is a difference between disability as a personal self-identified ('I am disabled'), which may or may not carry a political connotation for that individual, and disability as an identification by others; the other-identified disabled person may fit more closely with the paradigmatic disabled person, or be visibly identified as disabled through use of an assistive device.

The ways in which disability are constructed can be divided in terms of the medical and the social, which can be understood as broadly in opposition to each other; as the names imply, medical understandings focus on diagnosis, while social understandings focus on the social constructions of disability and difference. This chapter will lay out

¹¹ An example of this are people who see me walking with my stick and assume either that I carry my stick a fashion statement (because I don't fit the paradigm – I am not 'old enough') or who speak to me loudly and slowly, assuming I must also be deaf and/or have a cognitive impairment stopping me from understanding verbal communication. This is not to say that individuals cannot have multiple impairments, however – just that being disabled in one way does not automatically mean being disabled in others.

the main theoretical models used to understand disability and the lived experience of disabled people, beginning with the medical/individual and social models. It will then go on to discuss some of the critiques levelled at the social model, before exploring how crip theory has developed out of these critiques and further consideration of the lived experience of disabled people. The central concept of crip theory, compulsory able-bodiedness (or, in my preferred term, able-bodymindedness¹²), will be explored in conjunction with the ideal of the normal human, dis/ableism, and how the disabled person becomes the object of stigma and abjection in neoliberal society. The notion of crip time will be considered. The chapter will conclude with a brief consideration of crip as identity for nondisabled people.

A Brief Mention of the UN Definition

The United Nations' (UN's) official Decade of Disabled Persons¹³ ran from 1983 to

¹² See p.20 on language choices.

¹³ The UN will declare a decade in which to focus on a particular social group to promote "international awareness and action on these issues" (United Nations, 2016). 2016 marks the beginning of the United Nations Decade of Action on Nutrition, although there are also six other decades being observed as of October 2016.

1992, and showed a change in the UN's formal definition of disability from medically-focused welfare principles, to a rights-based approach more in line with the social model of disability.¹⁴ In the 1980s, the UN used the World Health Organisation's definition of disability, called the International Classification of Impairments, Disabilities and Handicaps; the ICIDH divided disability into three parts, with impairment defined medically, disability as the lack of function resulting from impairment, and handicap as the social disadvantage suffered by an individual on the basis of impairment or disability (United Nations, 2004). Wendell critiqued this understanding, writing that "the definitions of 'impairment' and 'disability' seem to imply that there is some universal, biologically or medically describable standard of structure, function, and human physical ability" (Wendell, 1996, p. 14). The definition of handicap largely ignored differences in location and gender (Wendell, 1996), while others critiqued it as too medical and individual (United Nations, 2004).

The more recent Convention on the Rights of Persons with Disabilities reflects the social model, rights-based approach, defining 'persons with disabilities' (rather than the social model's preferred term, 'disabled people') as including "those who have long-term physical, mental, intellectual or sensory impairments which in interaction with various barriers may hinder their full and effective participation in society on an

¹⁴ See p.46.

equal basis with others” (United Nations, 2004). The definition given by the UN is a response to the work of disability rights activists and disability theorists, and is largely a legal definition, rather than an explanation of a social construct; while the acknowledgment of disability as a ‘special’ or ‘minority’ category¹⁵ in need of protection and support is a welcome one, the definition can be considered largely superfluous in the context of this thesis.

Medical model and individual model

The most common, and perhaps most widespread – at least in the global North – understanding of disability is known, variously, as the medical, the individual, or the tragedy model, but the three terms can be understood as largely the same, with a slight shift in critical focus which depends on the position of the speaker. It should be noted, at this point, that the model is not a model in terms of describing what disability is, but rather how the concept of disability is understood and applied to individuals designated as disabled.

¹⁵ Other special categories for the UN include children, women, migrant workers, minority ethnic groups, and indigenous peoples; there is little acknowledgment that an individual might occupy more than one categorisation.

To put it simply, the medical model posits disability as a medical issue; medical knowledge identifies what constitutes disability, medical diagnosis identifies those individuals with a particular disability, and through medical intervention and treatment that disability is either overcome or mitigated. The ‘tragedy’ part comes in once medical diagnosis and intervention has been made; if the diagnosed individual cannot be *wholly* cured by medicine, their remaining disability is a tragedy, blighting their lives and the lives of their family and friends, but it remains no more than an individual problem, and thus can only be dealt with at the level of the individual. Once medicine has done all it can in terms of cure or rehabilitation, the disabled individual (and their family) must deal with a situation as best they can, without interference or support from wider society, beyond that of charity or philanthropy; society is positioned as having no impact on how disability is experienced. Disabled people are positioned as figures of pity (Gillespie-Sells *et al.*, 1998; Kafer, 2013), and frequently as recipients of charity, or as tragic objects. The disabled person’s loss of status – or potential for status, for those diagnosed before or at birth – which they had as a non-disabled individual is a tragic one, if only from the point of view of non-disabled outsiders, although it is frequently imagined that disabled people also view themselves as tragic or pitiable figures.

The 'individual' label comes from the understanding within the model that disability is an individual problem – an individual is diagnosed; an individual's life is blighted by tragedy. It also positions response to disability as the duty of the individual, and in the form of charity; there is no need for social, collective response, no responsibility for the state to provide support or assistance,¹⁶ or to make changes to the law or the built environment in order to improve the lot of disabled individuals. Whether the focus is on medicine, the individual, or the tragedy, the three approaches are largely unified in their positioning of disability as an individual's tragic medical condition; it is important to remember, however, this understanding is not restricted to medics and medical professionals (Kafer, 2013).

Within the medical model, diagnosis plays a central role; without a diagnosis one is not recognised as disabled. "Diagnostic labels create particular pathologies, which are assumed to be an embodied part of individual identity, create individuals as subjects of professional intervention, and play a role in the maintenance of professional power" (Yates, 2005, p. 66); diagnostic labels act as gatekeepers for access to support, including medical care. It is important to consider that only particular individuals, with

¹⁶ Somewhat ironically, assistance is constructed as something that only certain individuals need, rather than the consequences of living socially, rather than completely self-sufficiently and hermit-like (Wendell, 1996); see p.48.

appropriate knowledge and training, are able to make diagnoses and label particular bodies or minds as impaired or diseased. Diagnostic labels also act as indicators of pathology, as indicators of a bodymind being distinct from the normal, and “with the advent of the distinction between the normal and pathological, it becomes possible to see impairment and to say disability; in addition, disability becomes discursively constituted as a physical or mental *deficit*” (Hughes, 2005, pp. 82–83 italics added), and thus the acquisition of a diagnosis is positioned as a tragic event. Bodily or mental difference is, through pathologisation, positioned in such a way that the deficit body *requires* medical care; as Sherry states, “the medical model has persistently conflated the unusual with the unhealthy” (Sherry, 2004, p. 781), and while medical intervention may be desired by the disabled person, the assumption is that *all* disabled people are unhealthy, and both require and want medical care.

Disability, positioned within the medical model as a deficit, as a lacking, “is assumed to be ontologically intolerable, that is, *inherently* negative” (Kumari Campbell, 2005, p. 109 italics original), and pathologising disability delegitimises the person (Hughes, 2005), with personhood presented in opposition to disability (Titchkosky and Michalko, 2012). Within this understanding disability is “framed as a ‘problem’ typically [generating] the requirement for explanation and amelioration, but little else” (Titchkosky and Michalko, 2012, p. 127), and moreover, disability is presented as

“a knowable fact of the body” (Kafer, 2013, p. 4) which can be easily demonstrated to nondisabled people through a few hours use of a wheelchair or blindfold; while such activities often succeed in generating sympathy for disabled people (further reinforcing the position of disability-as-tragedy), they are not particularly good at demonstrating the practical problems and social injustices faced by disabled people over their lives – and are utterly useless when it comes to understanding disability as a political identity.

The ontological intolerability of disability is at the heart of the medical model, assuming disabled people not only need, but want, medical intervention and rehabilitation, when instead many disabled people experience “the medical encounter as a power relationship with oppressive repercussions. The coldness and formality, the lack of privacy, the objectification of the patient, the lack of communication, and the voyeurism constitute a form of violation” (Shakespeare *et al.*, 1996, p. 142). While medical care may be welcomed by disabled people at various times, and even deemed necessary by them (Kafer, 2013; Sheppard, 2012), medicine is in a position of power, as the holder of knowledge (of the disabled body) that is deemed superior to the lived experience of the disabled person; the disabled person is reduced by the medical gaze to an object of study, an object of rehabilitation – and when their rehabilitation fails to return them to proper ableness, a tragic, deficit, object of pity, a failure. Within the

context of acquired disability – such as that caused by injury or disease after birth – becoming the object of medical care is often experienced as a loss; a loss of power over one's own body, and of the knowledge of that body, with medical professionals having both knowledge and power (Sullivan, 2005) over the objectified body. In addition to being experienced by disabled people being objectified through medicine, there is also the assumption that an acquired disability is particularly tragic because it involves the loss of ableness – and thus the position of subject – most notably so when the individual is a child or young adult, and has therefore lost not just current ableness, but the *potential* of an able future.¹⁷

The body in medicine is a machinic one, with parts that can be replaced (Grosz, 1995) if they cannot be fixed. This ties into eugenics and normalisation;¹⁸ just as genetic 'disability' must be edited out (Wilson, 2006), so must the disabled body-object be brought back under control, firstly through the work of medics within medical institutions, producing docile bodies (Sullivan, 2005) that strive for proper self-control.¹⁹ Rehabilitation²⁰ is assumed to be a promise – assumes that disability is

¹⁷ See p.76 for further discussion of futurity.

¹⁸ See p.59.

¹⁹ See p.123 for more on control.

unwanted and unwanted – and thus assumes that a disabled identity must always be lesser to a non-disabled one, that individuals would rather be able-bodied, ²¹ and that disability is an unwanted state (Kumari Campbell, 2009; McRuer, 2006).

The Social Model

The social model, originally developed in the 1970s by academics working with the grassroots disabled people's collective UPIAS²² (Barnes *et al.*, 2002; Goodley, 2014; Goodley *et al.*, 2012; Oliver, 1997, 1996), was positioned explicitly and directly in contrast to the medical model. Influenced by political and social activism, the social model divided disability into two parts, impairment and disability. Impairment is medically-defined lack or deficit, the answer to 'what's wrong with you?' and the base upon which disability is built. Disability, in contrast, is forced onto people with particular impairments by the structures of society, culture, and the built

²⁰ See p.118 for more on rehabilitation.

²¹ Even when they may not wish to, or may feel that they have to engage with the whole of rehabilitation, rather than particular aspects, and this whole engagement is a form of gatekeeping.

²² The Union of the Physically Impaired Against Segregation.

environment. In the view of the social model a person is disabled by society,²³ and only through changing society – rather than rehabilitating their bodies – will they cease to be disabled. That said, disability as understood by the social model is not as straightforward as the initial division into impairment and disability; the social construction of disability is multi-faceted and complex, it is gendered and racialised, and what constitutes impairment varies globally, is impacted by violence and inequality as well as by genetics and accident (Wendell, 1996).

In Susan Wendell's words, "the disability in a given situation is often created by the unwillingness of others to adapt themselves or the environment to the physical or psychological reality of the person designated as 'disabled'" (Wendell, 1996, pp. 29–30). The explicit and implicit actions of a society that create disability can be at once easy to identify, such as open hostility towards visible bodily difference and built spaces that can only be accessed by stairs, but others can be harder to discern. For Wendell, it is expectations of normal activity and ability that underlie "the social construction of disability through expectations of performance" (Wendell, 1996, p. 37). These expectations of normal bodily performance – such as walking, holding utensils, and turning the pages of a magazine – are heavily gendered; as Young points out, women and girls can be considered physically limited in terms of their abilities to

²³ Hence the preference for 'disabled person' rather than 'person with a disability' (see p.20 for a brief discussion of language).

use the full potential of their bodies, due to the demands of performing 'proper' gender deportment (Young, 1980). However, this societally-imposed limitation is not considered a disability, in that it is also the norm; it is only when bodies' performance differs from the gendered (and also racialised and sexualised) norm is it noticed. Thus, just as bodily performance expectations are gendered, the differences from the norm which are marked as disability are also gendered – women are marked as disabled when their bodily performance differs from that of the 'normal woman,' not when she cannot perform as a masculine body is expected to. Wendell goes on to explain that there are normative expectations around social participation – particularly in the form of undertaking paid employment – which further act to disable people, as "It is only when people need a different kind or amount of help [to access services or employment] than that given to 'paradigm' citizens that it is considered help at all, and they are considered socially dependent" (Wendell, 1996, pp. 40–41).

In the social model, being disabled is feared by non-disabled people in society, just as ageing, illness, and pain are also feared, but "fear of all of these things ... means that there is little cultural representations which creates an understanding of their subjective reality" (Morris, 1992, p. 164). This fear, increased by a lack of cultural understanding, acts to position disability (as well as ageing, illness, and pain) as the problematic other, reflected in social factors that create disability itself. Disability

becomes a problem for non-disabled people because it forces them to confront their own fragility; disability is a possible future problem for them, perhaps an inevitable one as people age and become more frail and dependent on others, or one that could occur suddenly through illness or accident, placing themselves or those they care for in the position of problematic disabled other, in a situation that is presumed to be ontologically intolerable²⁴ (Kumari Campbell, 2009). This “phenomenon of problem,” as Titchkosky and Michalko put it, “while generating the sense that problems are inevitable and all people have them, also releases the possibility for people themselves to be understood as a problem. Thus, while everyone has problems, not everyone *is* a problem. Disability is not only a problem that some of us have, we are also *the* problem that others have” (Titchkosky and Michalko, 2012, p. 134).

The social model does not necessarily seek to promote disability as a social identity (because, as a model, it does not seek to do anything), although it was rooted in the disability rights movement, and has since been used by academics and organisations that do position disability as an identity. As a tool, the social model can demonstrate how acquiring disability can lead to changes in attitude towards the newly-disabled person from others, but also from themselves (Shakespeare *et al.*, 1996). For many disabled people, Shakespeare *et al* (1996) posit that having a disabled identity comes

²⁴ see p.44.

in two stages; first is becoming disabled according to the social model, based on impairment, then the disabled person 'comes out' as disabled, embracing their social identity as a disabled person. This 'coming out' is explicitly based on the concept and experience of coming out as a queer, lesbian, gay, or bisexual person (McRuer, 2006; Shakespeare *et al.*, 1996; Whitney, 2006), with the disabled person publically claiming an explicitly political identity as well as one assigned by others, based on a socially significant difference from the expected/normal (in the form of not being heterosexual, or having an impairment or diagnosis). While the 'coming out' analogy may not be totally identical, the significance of a politicised self-identification is an important aspect of both, in addition to the shared social history of queer and disabled people.²⁵ The positive identity claimed on coming out is not necessarily found earlier in life by people disabled from birth or early childhood,²⁶ as parents of disabled children may discourage them from developing a disabled social identity, albeit with the best of intentions (Shakespeare *et al.*, 1996), not wanting their children to identify themselves in the medical/tragedy model, which places their lives as tragic and intolerable, or perhaps basing their actions on a belief that "the general negativity of public representation [of disabled people] simply reflects the facts of life" (Shildrick, 2009, p. 57).

²⁵ see p.64.

²⁶ Whether through genetic 'disorder,' illness, or accident.

The social model has been joined with the medical model in the much-critiqued and reviled biopsychosocial (BPS) model, which while it started out as a theory, is frequently regarded as less a theory and more of a policy adopted by neoliberal governments to justify cutting state financial support for disabled people (Bendelow, 2010; Marks, 1999; Nielsen and Fernandez, 2010; Thorburn, 2012). From a BPS viewpoint, disability and illness are a combination of biology (nature and the body), psychological (mental illness and ‘attitude’) and external social factors; having the right attitude²⁷ is as much a key aspect of rehabilitation and recovery as medical care, and a wheelchair-accessible environment. The BPS model has been criticised for focusing on the *B* and the *P* aspects, and ignoring the *S* (Nielsen and Fernandez, 2010), and in Bendelow’s words, “for not fully addressing mind/body dualism, as the patient can still be compartmentalised by the physical addressing biomedical symptoms and the psychosocial element by the psychologist or psychiatrist” (Bendelow, 2010, pp. 22–23); in effect the BPS model can be seen as the medical model disguised with social model language. While at first look the BPS model might appear to be helpful – and indeed it has often been a critique of the Social Model that it ignores the body, while the Medical/Tragedy model ignores the social,²⁸ so a model that takes the ‘best’

²⁷ See p.126 for more on ‘the right attitude’.

²⁸ See the next section starting on p.52.

of both seems like the obvious answer - it has from the outset been so politically problematic (Morris, 2013; Thorburn, 2012) that it cannot be rehabilitated. In effect, the use of the BPS model as a part of the justification of cuts to welfare support for disabled people (as well as for unemployed people) has meant that it has never gained much in the way of support from disabled people themselves, unlike the Social Model; it would be difficult to rehabilitate a BPS approach while also claiming an emancipatory approach to disability.²⁹

Beyond the Social Model

The social model has seen its share of critique, a great deal of which focuses on the social model's strict constructionism, which "either fails to account for the difficult physical realities faced by people with disabilities or presents their bodies in ways which are unrecognisable to them. These include the habits of privileging performativity over corporeality, favouring pleasure to pain, and describing social success in terms of intellectual achievement, bodily adaptability, and active political participation" (Siebers, 2006, p. 175). When it comes to favouring intellectual

²⁹ see p.188 on emancipatory research

achievement, the social model's roots in UPIAS³⁰ (the now-defunct Union of the Physically Impaired Against Segregation) have perhaps lead to it being particularly exclusionary toward people with cognitive impairments and learning disabilities; in seeking to demonstrate how people with physical impairments were the victims of institutionalisation, it created a binary between physically impaired and learning disabled – further enforcing divisions between differing 'sorts' of disabled people already based on medical diagnosis.

In dividing disability into disability and impairment, the social model leaves impairment to medicine – it has no further interest in how impairment is constituted beyond medical diagnosis, and therefore no interest in the body. In the view of Hughes and Patterson, the social model “makes no concession to constructionism or epistemological relativism; it posits a body devoid of history ... devoid of meaning, a dysfunctional, anatomical, corporeal mass obdurate in its resistance to signification and phenomenologically dead, without intentionality or agency” (Hughes and Paterson, 1997, p. 329). This lack of engagement with the body can often be expressed as a lack of engagement with the frailties and limits of bodies with impairments, even as feminist disability scholar Morris (1992) argued that denying frailty as an aspect of disability limits the ability of all disabled people to form a social

³⁰ See p.46.

identity on the basis of disability itself.

The social model's lack of engagement with medicine can go as far as a wholesale rejection of the medical institution, which, as Kafer points out, "can marginalise those disabled people who are interested in medical interventions or cures ... a strict social model completely casts cure out of our imagined futures; cure becomes the future no self-respecting disability activist or scholar wants. In other words, because we are so often confronted with the medical framing of disability as unending burden or as a permanent drag on one's quality of life, disability rights activists and scholars tend to deny our own feelings of pain or depression; admitting to struggling with our impairments or to wanting a cure for them is seen as accepting the very framing we are fighting against" (Kafer, 2013, pp. 7–8). While challenging the discourses of medicalisation³¹ and of medical institutions is both necessary and productive, focusing on social structures while excluding medicine completely is unproductive, and consigns vast swathes of the experience of disabled people to silence.

Feminist approaches to disability have challenged this silence, having been engaged with bodies, phenomenological experience, and corporeality while attempting to

³¹ See p.40 on the medical model, and pp.96, 118 on discourses of medicine, pain, and rehabilitation.

bridge the gap between the social model and bodies. Wendell calls for a balance between social construction and “thinking of a body’s abilities and limitations as given by nature and/or accident ... to acknowledge that social justice and cultural change can eliminate a great deal of disability while recognising that there may be much suffering and limitation that they cannot fix” (Wendell, 1996, p. 45). Crip theory³² goes further than this, critiquing the concept of limitation itself, while also building on the parallels between disabled and queer communities extend beyond coming out into “medicalization, simultaneous asexualisation and hypersexualisation and institutionality” (Whitney, 2006, p. 40).

Crip Theory and Dis/ability

*“people – crippled or not – wince at the word ‘crippled’ as they do
not at ‘handicapped’ or ‘disabled.’ Perhaps I want them to wince ...
As a cripple, I swagger”* (Mairs, 1992, p. 9)

The quotation above, from Nancy Mairs’ essay *On Being a Cripple*, demonstrates the contestatory, challenging, questioning nature of crip, an approach that engages with the risks, exclusions, pain, and unpleasantness of disability (Kafer, 2013). Crip sees

³² See the next section beginning on p.55.

disability as “a potential site for collective reimaginings” (Kafer, 2013, p. 9), and actively rejects essentialism, seeing disability as not a fixed state (Sherry, 2004) but as a fluid, debateable, collective affinity (Kafer, 2013) based on an experiential and self-expressed identity; crip is both negative and positive, embracing all aspects of disability rather than silencing those aspects it is difficult or impossible to find joy in.

Crip theory is a critical approach centralising the role of compulsory able-bodiedness, or ableism, in neoliberal society³³ (Goodley, 2014; Kafer, 2013; Kumari Campbell, 2009; McRuer, 2006). Crip theory takes its cue from queer theory, critiquing the idea of a socially-constructed ‘normal’³⁴ through a concept of disability which owes much to the social model; crip theory develops how modern-day society enforces not just what constitutes disability, but places the non-disabled, unimpaired body as the normal – and normative – experience, as well as the ideal. McRuer (2006) called this compulsory able-bodiedness – taking inspiration from the idea of compulsory heterosexuality (Rich, 1994) which underpins queer theory. Kumari Campbell (2009), among others, develops this concept in the term ableism, and its partner, disableism – more briefly characterised as dis/ableism (Goodley, 2014).

³³ See p.70 for more on neoliberalism.

³⁴ See p. 59 for more on the concept of ‘normal.’

Ableism, in Kumari Campbell's words, can be considered as "inscribing certain bodies in terms of deficiency and essential inadequacy [which] privileges a particular understanding of normalcy that is commensurate with the interests of dominant groups (and the assumed interests of subordinated groups) ... [requiring] the normate individual to depend upon the self of 'disabled' bodies being rendered beyond the realm of civility, thus becoming an unthinkable object of apprehension" (Kumari Campbell, 2009, p. 11). To unpick this notion then requires a consideration of what constitutes 'normal' – normal bodies, normal minds, functioning in normal ways – and how this underpins concepts of what it means to be human – and how the disabled, abnormal body or mind needs to be continually defined and pointed-out in order to maintain a position of normality; the normal cannot exist without the abnormal, and it is far easier to define what abnormality is. Being normal – or perhaps being not abnormal – conveys privilege in much the same way heterosexuality or whiteness does; it is assumed as the default, but also as the ideal, the position to be aspired to, which requires maintenance. "Ableism," Hughes writes, "rests on the effort to eliminate from awareness, chaos, abjection, animality, and death: all that civilization seeks to repress. It encourages us to live in the false hope that we will not suffer and die, to adopt a perspective of invulnerability, to confuse morality with beauty and to see death, pain and disability as the repulsive woes of mortality rather than as the existential basis for community and communication" (Hughes, 2012, pp. 252–253).

Disableism can be considered the *active expression* of ableism (Goodley, 2014) – how ableist notions of normal, civilised, proper humanity are expressed in terms of acts of prejudice, aggression, and dismissal. This concept has clear roots in the social model of disability; disableism is the social process of disabling described in the social model as causing disability, but theorising dis/ableism is more firmly engaged with the body. The abnormal body, and the normal body are understood as social; disability “is a product of discursive practices ... The re-iterative power of discourse perfects the performance so that the body not only becomes the materialisation of its diagnostic labels, but also its own set of constraints and regulations” (Hughes and Paterson, 1997, p. 333). Crip theory seeks to consider the phenomenological experience of disability at the same time as considering how it is constituted. In this way, it examines the experience of disability, in terms of living with a disabled bodymind, not just in terms of the pains and fatigues that result from differences of the bodymind, but also in terms of how that difference is discursively constructed as a diagnosis and disability, and how that construction affects how disability is experienced.

Compulsory able-bodymindedness relies on certain bodymind forms becoming constituted as lacking; it “requires the [normative] individual to depend upon the self of ‘disabled’ bodies being rendered beyond the realm of civility, thus becoming an

unthinkable object of apprehension” (Kumari Campbell, 2009, p. 11). The fear of the disabled other, and the constitution of that other independent pins what is normal – that which is not abnormal – in the same way as the monstrous queer haunts compulsory heterosexuality, the monstrous crip haunts compulsory ablebodymindedness. Being normal is defined through the bodyminds of abnormality – and fear of that abnormality ensures that being normal is continually strived for.

The normal human

Conceptions of what constitutes ‘normal,’ including the normal range of abilities, are relative from culture to culture and change over time. Perceptions of normal in much of the global North – particularly measurements of averages – are rooted in 19th-century eugenics (Davies, 2006). Although notions of ideal or everyday bodies and lives existed before this point, particularly in philosophy and art, the development of science and, in particular, medicine gave rise to the concept of a normal body as a quantifiable entity, describable in terms of placement on a bell curve (Davies, 2006). The quantifiable body, one that can be described as normal or abnormal, is not a fixed entity in time and across all societies; there is no rigid division between normal and abnormal; what is abnormal and what is not is continually changing, as well as being heavily racialised, gendered, classed, and sexualised. In addition, as Wendell points

out conceptions of normal abilities “depend on how much is necessary to perform the most common tasks of daily living in a particular physical and social environment” (Wendell, 1996, p. 16); what is normal, and what is ideal, changes depending on what roles those normal bodyminds need to do, and the resources ‘normally’ available to them.

The measurements of bodyminds produced by the drive towards a medical understanding of normality served not only to provide a quantifiable value which could be deemed the statistical norm – such as intelligence, height, weight, and age of death – but also reinforced eugenicist ideas of who should and should not procreate, what Davies refers to as the need for “the state to attempt to norm the non-standard” (Davies, 2006, p. 6), and to create the perfectible human. That eugenicist aim to ‘improve’ white Western people through selective breeding required that certain measurable types of people be removed from the population, through incarceration, and also through compulsory sterilisation. This can be observed in such policies as that of incarcerating those deemed ‘feeble-minded’ in the late 19th and early 20th centuries in America, which aimed both to protect certain ‘idiots’ from neglect (and their families from the burden of their care), and to protect society from so-called ‘moral imbeciles’ (Carlson, 2005). As Carlson points out “as the definitions of feeble-mindedness shifted to reflect the close association with a morality, giving birth

to more than one child outside her marriage became a 'sign' of feeble-mindedness ... While the 'feeble-minded' woman was a danger to society by virtue of her procreative powers, inside the walls of the institution she could nurture and protect her surrogate children," (2005, p. 143) as she was forced to labour within the institution as a carer for other inmates.

For Tremain (2005) the description/prescription of norms is a key part in the apparatus of biopower; normality is positioned as desirable, but normal and normalised subjects are also governable ones; normalisation produces a docile body, one that fulfils its role as a productive worker. For Best (2007), this is tied much more to a reflexive self, in that normality is something we apply to ourselves and measure ourselves against. In this reflexive application of normalisation, "normality ... Is seen as a challenge, something that can be designed and produced, is a phenomenon that changes with time. Normality is no longer an external constraint that society imposes on its members; it is formed and shaped by acting subjects themselves. The conception of normality that currently prevails could in other words be termed *flexible-normalistic*" (Waldschmidt, 2005, pp. 191–192, italics original). Tremain, Best, and Waldschmidt all take their cue from Foucault, who when discussing medicine stated that it is concerned with "a knowledge of *healthy man*, that is, a study of the *non-sick man*, and a definition of the *model man*... It assumes the normative posture,

which authorises it not only to distribute advice as to healthy life, but also to dictate the standards of physical and moral relations of the individuals and of the society in which he lives” (Foucault, 1973, p. 34, italics original).

These conceptions of what is normal (and thus what is abnormal) form a key part of discursive constructions of various forms of knowledge, particularly those around medicine, psychology, criminality, and sexuality. In the same way as bearing children outside of marriage once made one ‘feeble-minded,’ being anything other than heterosexual made one either mad, criminal, or both; expressions of sexuality outside of the norm (as defined by the moralities of those with particular forms of knowledge) were treated in much the same way as disability itself (Davies, 2006; McRuer, 2006). While explicitly eugenicist aims may have fallen out political favour, the impact continues in terms of the discursive construction of who is, or is not, disabled, and the continued inclusion of BDSM in the DSM.³⁵

Practices based in eugenics, such as institutionalisation and IQ testing, “justified

³⁵ Diagnostic and Statistical Manual of Mental Disorders, published and regularly updated by the American Psychiatric Association; homosexuality was specified as a mental disorder in the DSM until 1973 (and arguably not wholly removed until 1987).

disabled people's sequestration; the-based clientele in order to further secure their exclusion from the rights and privileges of the majority of society; sought to physically restrict them from opportunities to procreate; shifted their representation in the dominant culture from misfortune to menace" (Snyder and Mitchell, 2006, p. 135). These exclusions are echoed now in segregationist schooling practices, lack of access to public space and public interaction, and the widespread conception of global disability and shared commonality. Furthermore, the language of inclusion has been incorporated into neoliberal regimes of 'inclusion' marked by regimes of rehabilitation and normalisation³⁶ which have "been welcomed not only by the generality but also by many strands of disability rights activism, where attainment of similar rights to other citizens – even at the cost of both further marking down those left behind and taking on a certain invisibility oneself – has been unproblematically celebrated" (Shildrick, 2015, p. 12). This limited, but visible, inclusion reinforces structures whereby those who are not included can be blamed for their exclusion – saying they are being 'difficult' or not making use of the practices of inclusion (regardless of whether such adaptations are actually useful or useable), while also making invisible those disabled people who can be normalised.

The same conceptions of normality and the same normative postures that produce

³⁶ See p.118.

segregationist schooling practices dictate the standards of sexual norms for non-disabled as well as disabled individuals – and position disabled people as both asexual and monstrous in their sexuality.³⁷ Gender, sexuality and disability are tied up together; as Rembis points out, “ultimately what becomes disabling for most people is a failure to perform gender and sexuality in a way that approximates what Butler calls the ‘phantasmic idealization’ of heterosexuality” (Rembis, 2010, p. 52). For McRuer, compulsory able-bodiedness³⁸ is the system “which in a sense produces disability, [and] is thoroughly interwoven with the system of compulsory heterosexuality that produces queerness ... in fact, compulsory heterosexuality is contingent on compulsory able-bodiedness, and vice versa” (McRuer, 2006, p. 2). Compulsory able-bodiedness gives the illusion of choice, and are constructed in such a way as to appear natural (McRuer, 2006; Wendell, 1996). Sherry (2004) draws a picture of the similarities between the experiences of queer and disabled people; familial isolation, high rates of violence, discrimination, stereotyping, emotional trauma, passing, disclosure, and coming out, exclusion from politics, parodies of experiences used political tools, and a lack of access to full citizenship. “In the same way that is the social model theorists have pointed to the dominant culture as responsible for the creation of disabling environments and attitudes, some queer

³⁷ see p.132 for a further discussion of normality and sexuality.

³⁸ See p.56.

theorists pointed to the way in which the dominant culture and its family environment are responsible for creating inequalities in public access to various forms of pleasures and possibilities” (Sherry, 2004, p. 775); this is reflected in Siebers’ call to co-think sex and disability in order to reveal “unacknowledged assumptions about the ability to have sex and how the ideology of ability determines the values of some sexual practices over others” (Siebers, 2012, pp. 38–39).

Stigma and Abjection

Stigma is cast upon us due to “an undesired differentness from what [others] had expected” (Goffman, 2006, p. 132); in the case of disabled people, that differentness is from the expected norm, and disabled people can either live with stigma, try to cure their difference, or overcome stigma through excelling in some other area, such as sporting prowess. In the case of disability, stigma is closely tied to abjection, which, in Kristeva’s words, is a challenge to order – “it is thus not lack of cleanliness or health that causes abjection but what disturbs identity, system, order. What does not respect borders, positions, rules. The in-between, the ambiguous, the composite” (Kristeva, 1997, p. 232). Abjection requires containment in certain bodies, in the bodies of certain others (McRuer, 2006), and it creates spaces and zones of exclusion (Tyler, 2013) – both physically (in terms of inaccessible spaces and segregated education) but

also in a wider discourse of 'them' and 'us,' of othering.

Stigmatised bodies are those which are repulsive, disgusting, abject – due to a fear of disability, a horror of bodily difference (McRuer, 2006; Shildrick, 2009) the discursively normal subject expresses this disgust, this abjection, as a “response to that stuff which threatens to overwhelm their body border and their attempts to turn away and distance themselves” (Tyler, 2013, p. 27). Disgust, as Miller (1997) points out, is often intertwined with fear, particularly fear of contamination, or fear of the possibility that the disgusted person could themselves become disgusting, become stigmatised through acquiring disability. Thus, stigmatised disabled bodies are horrifying and repulsive because they act as reminders of the fragility of normality – of how close the normal human is to being abnormal, or to being lesser (Miller, 1997). “At an existential level the presence of the disabled body is unsettling for non-disabled people who are often in denial about their own vulnerability. This is the psychological and emotional component of ... ableism” (Hughes, 2012, p. 18).

The disabled body is “out of control because of its appearance of uncontainability” (Kumari Campbell, 2009, p. 8). Bodies that wobble, that leak (Liddiard and Slater, in press), that are missing parts or with parts that don't work, that shout at the wrong time and twitch and mutter are all disabled bodies. Thus, “this notion of abjection

links the lived experience of the body, the socially and culturally specific meanings of the body, the cultural investment in selectively marking the body, the privileging of some parts and the functions while resolutely minimising or leaving un- or underrepresented other parts or functions” (Grosz, 1994, p. 192). However, as Kumari Campbell observes, “cultural practices of shaping bodies can affect the aetiology of ‘typical’ human functioning” (Kumari Campbell, 2009, p. 18), and so normality is culturally constituted and constructed, continually being made and continually shifting in its demands. As a result, for the non-disabled, there is a continual need to perform cleanliness and wholeness (Miller, 1997; Tyler, 2013), to perform able-bodiedness and demonstrate that one is not the abject; Kristeva’s “clean and proper body” (1997) is Hughes’ normative one (2012), and for Tyler (2013), abjection is contingent on expressions of normativity.

There is a moral judgement against failure to perform civilisation (Miller, 1997), to perform normativity (Hughes, 2012), and thus a moral judgement against being disabled, against receiving welfare, against needing assistance and failing to be properly independent (Kumari Campbell, 2009; Tyler, 2013; Wendell, 1996). Disabled people, along with migrants, people of colour, and benefits claimants, are national abjects, in ways that are different and the same, as “ideological conductors [are] mobilized to do the dirty work of neoliberal governmentality. They are symbolic and

material scapegoats, the mediating agencies through which the social decomposition effected by market deregulation and welfare retrenchment are legitimized” (Tyler, 2013, p. 9). Importance is therefore placed on passing as normal, as non-disabled – as properly rehabilitated and not at fault – precisely because “passing is not just about the impaired person hiding their impairment or morphing their disability ... [it] is about keeping the coloniser happy by not disturbing the peace, containing the matter that is potentially out of place” (Kumari Campbell, 2009, p. 44). However, as Tyler (2013) observes, ‘national abjects’ remain at the centre of public life even when they attempt to pass as normal, because they must be seen in order to be controlled; the threat of abjection is no threat without the visible abject. They are what Braidotti terms ‘disposable’ bodies, who “experience dispossession of their embodied and embedded selves, in a political economy of repeated and structurally enforced eviction” (Braidotti, 2011, p. 6).

In abjection, disability is a failure of a properly-controlled body, a failure of self-control³⁹ (McRuer, 2006), and an object of moral disgust, where “a physical experience of disgust slides into contempt and judgements of value. Yet because disgust is an emotion associated with involuntary bodily reaction, moral disgust is often experienced, or retroactively understood, as a natural response” (Tyler, 2013,

³⁹ See p.123 for more on controlled bodies.

pp. 22–23). It is this appearance of naturalness that ableism relies on in the system of compulsory able-bodymindedness. Within this, bodies must be civilised – must be controlled according to social norms (Miller, 1997; Williams and Bendelow, 1998); the sick body must be disciplined (de Wolfe, 2002), and doubt is cast on bodies that are not controlled. The risk/danger discourses that lead to what Williams and Bendelow (1998) call ‘surveillance medicine,’ identifying precursors of future illness or impairment feed into processes of abjection as “individuals are advised, cajoled and encouraged by health promoters to assess critically their risks of succumbing to disease and to change their behaviours accordingly. In doing so, a ‘victim-blaming ideology’ develops – one in which individuals are instructed to take responsibility for their health at a time when they are least able to do so (Williams and Bendelow, 1998, p. 71). The individual holds responsibility of their health, success, achievement, and so on, effectively depoliticising disability, and thus disability is “presented as a fact of life requiring determination and courage, not as a system marking some bodies, some ways of thinking, and patterns of movement as deviant and unworthy” (Kafer, 2013, p. 89); failure to perform, to be normal, to be independent and controlled and to perform taking control and engaging in rehabilitation, marks one as morally disgusting, as abject, as stigmatised – and therefore disability is “ontologically invalid or ‘uncivilised’” (Hughes, 2012, p. 18), and rehabilitation must cure or kill.

Neoliberalism

McRuer, Goodley, and others, see dis/ability and ableism as situated firmly in the practices of neoliberalism. Neoliberalism, for Tyler, is a context helping to form particular discourses, a form of governance that creates inequalities with public consent, through policies in support of the ‘free market,’ and without mainstream political opposition (Tyler, 2013); these inequalities cause ongoing financial and social insecurity for those in employment, along with a fear of becoming the abject⁴⁰ – with social abjection as the lot of those without incomes or who rely on welfare support (Tyler, 2013). The deliberate “precarization” (Tyler, 2013, p. 199) of labour insecurity, and the loss of collective agency brought about by increasingly precarious and insecure work across the majority of sectors, is accompanied by increasing demand for ‘flexible’ labouring bodies (McRuer, 2006), flexible to fit the changing demands of a precarious labour market, but also flexible in order to get ahead, to adapt in ways that mean they are able to continue working and producing. Those flexible bodies – immediately shaped through discourses of neoliberalism, but nonetheless framed in broader ideas of the normal and the ideal – are very specifically *able* at the same time, specifically “heterosexual, able-bodied ... [and able to] work with queer and disabled minority, flexibly contracting and expanding, while queer, disabled minorities

⁴⁰ See p.65.

flexibly comply. Because all of this happens in a discursive climate of tolerance, which values and profits from 'diversity' ... the heterosexual, able-bodied subject, as well as the postmodern culture that produced him or her, can easily disavow how much the subjective contraction and expansion of able-bodied heterosexuality (and ... neoliberal political and economic logics more generally) are actually compliant on queer, disabled bodies" (McRuer, 2006, p. 18). For Kumari Campbell, there is a tautology within neoliberalism – the discursive climate of tolerance specific to neoliberalism⁴¹ promotes inclusion, especially when difference can be cast as profitable or consumable, but the ableist discourse of flexible normativity casts disability as "inherently negative, ontologically intolerable and in the end, a dispensable remnant [of uncivilised times]. This casting results in an ontological foreclosure wherein positive signification of disability becomes unspeakable" (Kumari Campbell, 2009, p. 12).

Puar, however, situates neoliberalism as a more direct cause of failure itself, in that encounters with sociocultural and neoliberal-capitalist infrastructures may render the body's affective capacity inadequate (Puar, 2009). The effect of neoliberal policies – such as long-term precarious work causing stress and illness – creates what Puar (2009) terms debility, as do the constrictions placed on individuals and collective

⁴¹ Although discourses of tolerance are found outside of neoliberal regimes as well.

groups by neoliberal discourses. Shildrick identifies debility as inherently profitable; "it is in the interests of neo-liberalism to produce and sustain bodies as debilitated and therefore susceptible to a range of market commodities that hold out the promise of therapeutic interventions into the relative failures of physical, cognitive and affective embodiment" (Shildrick, 2015, p. 11); thus disability becomes failure to use those commodities – a failure of self-control – even though access to these may not be equitable and may not be appropriate.

Puar's conception of debility can also be seen as a loss of function, of ability – and in many ways can be read as disability, in that it is the requirements of modern life that cause a person's impairment to be diagnosed; for Shildrick (2015), debility is concerned with minor but prolific failures of the body or mind; but she is unsure if this approach is useful for disability, especially given that nobody escapes debility in some way. I remain unconvinced that debility has space for disability, agreeing with Mitchell and Snyder when they observe that "there is not a level playing field that all bodies occupy, and calling for a universalizing recognition of insufficiency will do little to accomplish meaningful systems change" (Mitchell and Snyder, 2015, p. 29). Debility, in positing an inherently negative view of itself, leaves no space for positive disabled identities – particularly those disabled people who do not experience their disability as a loss – and instead reinforces the ontological intolerability of disability, and rather

than “[indicating] new modes of egalitarianism ..., operate as a superficial rebranding of medicalised paradigms” (Inckle, 2015, p. 43). Finding a way for debility and disability to work together requires greater engagement with the ways in which disability itself is constituted as a lifelong state, compared to debility’s temporary nature, and with thinking around disability engaging with the ways in which the pace of life can be disabling.

Crip Time

The ever-increasing pace of life demanded by neoliberal society and 24/7 capitalism (Crary, 2013, p. 7), which Puar (2009) identifies as causing debility, for Kafer (2013) and Wendell (1996) is instead *disabling*. 24/7 capitalism demands workers who are capable of working hours independent of their local time zone – working early mornings or late nights, or at times that match the working hours of a stock market halfway across the globe – as well as workers who are able to meet continually-increasing expectations and continually-shortening deadlines. This acceleration of the pace of life, which is frequently debilitating for otherwise non-disabled individuals, can be further disabling for disabled people, as “when the pace of life in a society increases, there is a tendency for more people to become disabled, not only because of physically damaging consequences of efforts to go faster, but also because fewer

people can meet expectations of 'normal' performance; the physical (and mental) limitations of those who cannot meet the new pace of life become conspicuous and disabling ... for those who must move or think slowly, and for those whose energy is severely limited, expectations of pace can make work, recreational, community, and social activities inaccessible" (Wendell, 1996, pp. 37–38).

The expectation for performing heteronormative, flexible, independent, proper bodiliness, at the right time and in the right amount of time is a key aspect of disability, and a disabled body is one that fails to perform in a timely manner, whether it is failing to reach the right childhood developmental milestones at the right times, failing to sustain productivity, or failing to have 'normal' (read: heterosexual, spontaneous, 'vanilla') sex. Crip time, exploring the construction of time through a crip lens, is a somewhat humorous reference to disabled people's frequent need for 'extra time' that "might result from a slower gait, a dependency on attendants (who might themselves be running late), malfunctioning equipment (from wheelchairs to hearing aids), a bus driver who refuses to stop for a disabled passenger, or an ableist encounter with a stranger that throws one off schedule. Operating on crip time, then, might be not only about a slower speed of movement but also about ableist barriers over which one has little to no control; in either case, crip time involves an awareness that disabled people might need more time to accomplish something or to arrive

somewhere” (Kafer, 2013, p. 26). At the same time, crip time questions notions of ‘normal’ time – of when something should be done and how long it should take – and how time is itself a part of how disability is constructed. Thus, I would add To Kafer’s explanation of crip time notions of what constitutes ‘proper’ or ‘regular’ working hours, the notions of developmental milestones, and the experience of needing longer to respond to a question due to a ‘slower’ thinking process.

For Foucault (1973), time was a key part of the discourse of disease and medicine, both in the clinical gaze and in the progression of disease and recovery. Crip time then can also include diagnosis, prognosis, and progression of illness or impairment – chronic or acute, acquired or congenital, in remission, relapsed – as well as the very notion of prognosis and treatment itself. Development and chronological age are particularly important in terms of diagnosing disability/impairment in children (Rogers, 2009); asynchronicity between ‘mental age’ and chronological age is both a common descriptor of cognitive impairment for children, and a cause of discomfort/horror in those with normative expectations. This horror becomes quickly apparent when issues of gender and sexuality come into play, when ‘childlike’ minds inhabit ‘adult’ bodies capable of reproduction, and all the emissions and ‘mess’ reproductive maturity entails – let alone the sexual desires and ‘needs’ ascribed to sexually mature bodies; Kafer (2013) explores this more thoroughly in how it relates

to Ashley X and growth attenuation treatment for ‘severely’ disabled children.

Medically-framed constructions⁴² of disability are oriented through time in not just in terms of progression and prognosis, but also in regarding the future in curative terms; disability, like queer, is counter to progress and civilising processes (Kafer, 2013), and considerations of the future are frequently disability-free. For Kafer (2013), taking cues from the work of Edelman (2004), the figure of ‘the Child’ buttresses ableist heteronormativity – and the future Child cannot be disabled, just as the disabled Child of today must have a better future through rehabilitation, or no future at all. This bleeds into the fear of disabled people’s reproductive potential, either as inadequate parents of non-disabled children, or as inadequate parents of disabled children, forcing unwanted disability into the future through procreation.

Claiming Crip

The breadth of identities embraced by crip extends beyond those seen as more straightforwardly disabled; there is space in crip for more than just those disabilities

⁴² See p.40.

legitimised by diagnosis and recognition by government policy (Sandahl, 2003), just as there is space within queer for those who do not conform to normative models of cis-gender lesbian women or gay men. Within crip, arguments could be made that anyone and everyone can be crip, and claim a crip identity for themselves. Kafer asks if “claiming crip be a method of imagining multiple futures, positioning ‘crip’ as a desired and desirable location regardless of one’s own embodiment or mental/psychological processes? As McRuer notes, these practices run the risk of appropriation, but they also offer a vital refusal of simplistic binaries ... Claiming crip, then, can be a way of acknowledging that we all have bodies and minds with shifting abilities” (Kafer, 2013, p. 13; referring to McRuer, 2006). This last statement echoes Puar’s (2009) notions of debility, and again, it is problematic in that it can silence experiences of disabled identity and lifelong impairment; the non-disabled person claiming a crip identity may feel they are doing so in solidarity with disabled peers, but may instead be ‘disability-blind’, in the same way that being ‘colourblind’ denies the very particular experiences of people of colour.⁴³

⁴³ I am uncomfortable with the tendency within disability rights to appropriate terms that were developed by people of colour to describe their own experiences (such as ‘cripface’ to describe non-disabled actors playing disabled characters, from the term blackface), but at the same time, drawing parallels is sometimes an effective tool to illustrate a concept.

The blurring of distinctions between who and what constitutes crip – and who and what constitutes queer – results in difficulty defining both areas, even without acknowledging the overlapping and intersections of queer/crip experiences, but both notions are also characterised by - even *reliant* on – the disruption of normal,⁴⁴ and thus it is difficult to specify who is excluded by crip, and who cannot, or should not, claim crip. Kafer (2013) also considers how best to include those with impairments that others may recognise as disabilities, but who disavow a political, collective, disabled identity – people who do not want a disabled identity for themselves for a multitude of reasons. Imposing crip identities on them is as silencing as imposing unwanted disabled identities; their rejection of crip/disability often reveals much about the social standing of disability. For myself, including these people – and exploring why they reject a crip/disabled identity – is perhaps more important than bringing those without impairments, whose shifting abilities are better served by debility than disability.

⁴⁴ See p.59.

Chapter Two: Pain

At first glance, pain is not straightforwardly linked with disability, outside of medical understandings; the tendency of social model proponents to ignore the phenomenological experience of disability has meant that experiences of pain, fatigue, and weakness – as well as frustration, limitation, and difficult – have frequently been ignored or minimised.⁴⁵ However, in more recent development of the notions of ableism, compulsory ablebodymindedness, and crip theory, there is space to consider experiences and bodymind states which we can feel negatively or ambivalently towards.

This chapter explores understandings of pain, starting first with socio-cultural understandings – how pain is broadly understood, in social terms – and how we communicate pain. I continue with a brief look at times when socio-cultural understandings of pain are not negative, and give a short account of how pain is considered in various religions. As these sociocultural understandings are increasingly influenced by medicine – as is disability – I then consider medical understandings of pain, particularly chronic pain, and how medicine seeks to treat pain. Having taken

⁴⁵ See p.52.

what might be considered the medical model approach, the chapter will move on to considering pain in the context of disability, refocusing on arguments around whether or not pain constitutes a disability. This brings me to notions that lie parallel to, and intersect with, disability and compulsory ablebodymindedness: rehabilitation, control, and cure.

I have explicitly not included a detailed overview of medical knowledge about pain – the hows and whys of pain pathways and the like – in part because a consideration of such is beyond the scope of the thesis⁴⁶ but also because a detailed exploration of the biological mechanisms of pain would not add much to the thesis. Pain pathways are not well understood, even by medics specialising in pain (Boddice, 2015) – and while I like to think I have a decent non-medic’s understanding of the basics, I would hesitate to consider myself capable of properly digesting current medical research, let alone responding critically. This chapter does consider how medical knowledge and understanding around pain impacts wider social meanings,⁴⁷ as well as the interactions of people living with chronic pain with medics and care professionals – but it is largely suffice to say that pain is considered the domain of medicine, but a

⁴⁶ If I had a pound for every person who assumed this research was about how to *cure* pain, I would have enough to buy a really nice pair of shoes, or an academic book.

⁴⁷ See p.96.

detailed knowledge of medical views is not necessarily a part of that consideration; we can consign pain to medicine without fully understanding what we are consigning it to.

The sociocultural contexts of pain

Few people can say they have not experienced pain – indeed, the inability to feel pain is a part of several genetically-tied disabilities, and can be regarded as dehumanising (Morris, 1991), but the total inability to feel *any* pain from birth is rare enough that the reported figures for individuals with congenital analgesia are around the one in a million figure (Danziger and Willer, 2005). Even individuals with congenital analgesia have reported experiencing headaches when under severe emotional stress (Danziger and Willer, 2005); congenital analgesia does not affect an individual's ability to feel 'emotional' pain.

As Norridge (2010) writes of the transformative power of pain and injury, the experience of pain affects how an event is told, how a narrative is constructed. Pain is not the simple loop of sensation described above, found in school science books. The body and pain express meaning (Williams and Bendelow, 1998), and through this

meaning, “pain is not [simply] an intrinsic quality of raw sensation; it is a way of perceiving an experience. Pains are modes of perceptions: they are not the injury or noxious stimuli itself but the way we evaluate the injury or stimuli” (Bourke, 2012, p. 2). We assign meaning to the sensation of pain. It is the context in which pain occurs, and the context in which pain is expressed, that gives it meaning - pain is both somatic sensation and social construction, both experienced and interpreted (Morris, 1991). Pain is so much more than sensation, in that sensation does not happen in a vacuum – it is affected by context, by intent and the meanings we ascribe to it.

The sociocultural context in which pain – in which sensations – take place affect how that sensation is experienced, varying from body to body, from time to time, and from place to place. Pain is not straightforward and it requires explanations and interpretations (Best, 2007; Morris, 1991; Williams and Bendelow, 1998) that account for the sociocultural circumstances in which pain is experienced. Contextualising pain is important for pain to be understood, and even more importantly, to be understood and recognised as pain when we express it to others. Pain is not the same if it occurs in different contexts – if you stub your toe, then the pain that results is expected, and while painful, it is not of any great concern, unless you have (for example), recently had surgery on the toe, or a broken bone. An ache in your legs is relatively un concerning if you’ve been running for some time, but a stabbing pain when sitting

in front of the TV is rather more concerning. A cis-gender woman's period pain is considered largely normal, even when it causes her massive distress. The situations in which pain is regarded as normal – even expected – are highly gendered, with women's pain being regarded differently to men's, even as the pain of women of colour is regarded differently to the pain of white women. We shall return to the gendering and racializing of pain later.⁴⁸

Bendelow and Williams (1995) recount that people have *pain beliefs* – individualised, personal beliefs that affect how pain is experienced, and how we interpret our own and others' pains; these beliefs may or may not correlate with scientific understandings of pain, and are influenced by experience and personal history. The three dimensions of pain beliefs, which Bendelow and Williams summarise as “self-blame, perception of pain as mysterious, and beliefs about the duration of pain” (ibid. 1995, pp. 153–154) affect everything from the immediate sensation of and reaction to pain, to how that pain is later recounted to others, and how upsetting that pain was. The experience of pain is inseparable from its emotional and cognitive significance (Bendelow and Williams, 1995). However, “In Western scientific-medical culture, it is far more common to assume that states of mind that are caused by or associated with pathological states of the body are themselves pathological, and to dismiss both their

⁴⁸ See p.106.

perspectives and their content as illusory. This attitude, which seems to be based on a model of temporary illness, total recovery, and complete return to one's former self, makes it unlikely that we will be open to regarding illness and disability as either sources of knowledge or valuable ways of being" (Wendell, 1996, p. 68).

Research into culturally-constructed pain beliefs and reactions – starting with the studies of Zborowski (1952) in the 1950s⁴⁹ – demonstrate that bodies “cannot be understood as fixed or biologically given constants, somehow outside or beyond the constraints of power ... [bodies] are themselves produced and regulated as distinct phenomena" (Grosz, 1995, p. 218). While Grosz is talking of pleasure, the two are perhaps two sides of the same coin, both forms of sensation that are affected by culture and context, based on somatic sensation and emotion. If we accept that one somatic sensation is interpreted through discourse, then it is perhaps not so much a leap to view all somatic sensation as discursively interpreted, if not discursively constructed.

⁴⁹ Which while possibly insightful are also decidedly racist in tone; Zborowski divided his patients into racialised groups, and made gross generalisations – but he nonetheless demonstrated that reactions to pain, and pain beliefs were affected by wider social norms.

However, those discourses affect how we interpret and process pain; we engage all the time in activities which may or may not be interpreted as painful (Kleinplatz and Moser, 2007) – from getting tattoos to long-distance running, to boxing, to being flogged, to listening to loud music.⁵⁰ And yet, pain continues to be constructed and construed through discourses that continually say that pain is bad; there is an implicit assumption in discourses around pain, whether mental or physical, sought or inflicted, that pain is *bad* and undesirable; we do not – should not – desire to feel pain, and seeking pain in and of itself, is abnormal and repellent. There are times and situations where pain is acceptable (such as period pains or after a workout), and when pain is a necessary part of the process (such as childbirth, or getting tattooed), but at no point is that pain viewed as a positive sensation, at no point it is cast as *desirable* – only as necessary. This discourse spills over into discourses of illness; when a person is ill and feels pain, even when that pain is diagnostically useful, medical care should do everything to stop that pain and provide pain relief, and accepting pain as untreatable is only a last resort.⁵¹

The sensation of pain is, according to Seymour, “experienced as an attack on the

⁵⁰ See p. 92 for more on situations where pain has positive (or at least not-negative) meaning.

⁵¹ See p.96 for more on medicine and pain.

phenomenological and embodied self” (Seymour, 1998, p. 8), resulting in a renegotiation of how the person in pain lives, in the spaces of their lives and in their self (Norridge, 2010; Scarry, 1985); pain cannot be experienced *without* the self requiring remaking, without a renegotiation of the phenomenological self. The argument put forward is that pain, no matter its cause, is negative and destructive (Siebers, 2006), the result of violence and damage that is experienced as jarring, as breaking the boundary of the self, the skin, and our perception of our lifeworld (Norridge, 2010; Scarry, 1985). This understanding of pain means that pain is always ontologically negative – it cannot be lived with or endured, and it should not be sought. Pain, and the breaking of the self, is seen as a negative process – whether or not the end result is a positive one – but an infinitely more negative one when pain is unsought and unprepared for.

We divide pain into two halves; there is chronic pain, and there is acute pain; this binary division relies on time as a diagnostic tool.⁵² To take a medical understanding, chronic pain is that which lasts for a period of more than a few months (Thomas and Johnson, 2000) and has ceased to be diagnostically useful (Morris, 1991), while acute pain is that which does not last, that is temporary. When pain begins, it is always acute, and only when it continues does it become chronic; in this way, all pain is first

⁵² See p.73 for more on time.

experienced as acute – we assume that pain will soon fade away. However, pain does not have to be constant to be chronic – it can be recurring, its intensity can dim and flare up, and the adjectives used to describe it might change – but it does not stop, and when it dims, there is no assumption that it will not return, that it will cease to be.

Acute pain does not have to be unexpected – and to move outside of the strictly medical, it can be anticipated; we know a tattoo will hurt, that running for several miles will cause our muscles to ache even before we begin running. The difference is that acute pain is *assumed to be temporary* – while chronic pain is assumed to be unending. Death might bring about the end of both, and be positioned as a form of relief from pain, but when death stops acute pain, it is assumed to be violent, intimately related to the cause of that pain – while chronic pain does not *cause* death. Chronic pain is a side effect of disability, impairment, or illnesses which may or may not be terminal; the death of a person in chronic pain is a natural one, the end of a life that has been lived, while the death of a person in acute pain is a fundamentally unnatural one, an interruption of a life that has not been lived.

Acute pain has, in addition to the expectation that it will cease, a reason; chronic pain is frequently posited as either without cause, or meaningless (Morris, 1991); the two are somewhat different – to be meaningless, pain must not be instructive, it must not

be warning of danger or damage, it must not be teaching us something, and chronic pain has long since ceased to do that. When chronic pain is without cause, it is because the original injury has long since healed, or there is no discernible cause; the pain is experienced, but there is no injury, no underlying illness to respond to treatment (or an underlying illness that has no treatment, which is usually inexplicable, only vaguely understood, or of unknown cause, and all too frequently dismissed as 'psychosomatic'). Sometimes, the pain resists medical treatment, or responds poorly. Chronic pain lacks the significance of acute pain. Despite the construction of the two being very different, it is assumed that the experience of pain is the same – that pain is an ontologically negative experience and an attack on the phenomenological self.

Communicating Pain

Scarry (1985), writing primarily about torture – and therefore about pain that could be termed as *acute*, rather than chronic; pain with a reason for being – sees pain as resisting language; pain is inexpressible unless through animal sounds, metaphor, or simile. This inexpressibility means that we can remain unaware of another's physical pain unless we are informed of it, whether through words, sounds, or bodily clues that we can interpret as indicating pain. Scarry argues that even when a person is directly

and deliberately causing harm to another, they can only guess if pain is being experienced – and as a result, therefore, we can choose to ignore another’s pain, or to sympathise with their experience, but we will never truly *understand* their pain as they do (Scarry, 1985). Pain is only undeniably real when we ourselves experience it – and we rely on language to communicate what is real, the same language that pain resists; we use metaphors and similes in the hope of finding common ground and shared experience.

The weapon of torture, in the expression of pain, continues as the weapon in metaphor and simile (Scarry, 1985); we talk of a stabbing pain, as feeling like we’re on fire, of being bruised and broken. We *need* language to explain pain, and the language used is the key to unspoken – unspeakable – meanings (Bourke, 2012). Just as experiencing pain is a signifier of humanity – of being alive – being able to rationalise and describe pain is a signifier of being a proper human – in that the normal, proper human has the language skills and the knowledge of appropriate words to communicate a description of their experience, even if it can only be done once the urgency of acute pain has passed. The normal human⁵³ can bring their experience within language through metaphor and simile, even if that language is clichéd and restricted. This expectation of, and ability to, put pain into language, to contextualise

⁵³ See p.59.

pain, to make it accessible to others, creates the normative structure whereby pain is further restricted to the animal and the abnormal. This understanding of humanity is at once normative and ableist,⁵⁴ reflecting a worldview in which an able bodymind is both the ideal and the norm.

Physical pain, for Scarry, “has no referential content. It is not of or for anything, it is precisely because it takes no object that it, more than any other phenomenon, resists objectification in language” (Scarry, 1985, p. 5). However, this resistance to objectification through language leads to pain being painted as somehow *beyond* language - that language cannot express pain adequately, and suggesting that it is the problem of *expression*, rather than the problem of *hearing*. In this, the problem of another’s pain not being fully comprehensible to the listener is placed as the ‘fault’ of the person in pain, their failure to express their pain adequately - perhaps in a properly normal human manner – rather than the fault of the listener – who might be unwilling to properly hear.

Pain – whether acute or chronic; much of the literature on pain does not distinguish between them – is positioned as beyond language and without referential content,

⁵⁴ See p.55.

and thus is assumed to have no significance beyond that of injury or damage. Pain is viewed as belonging firmly on the *body* side of mind-body dualism. This view is reinforced by those who posit that we only become aware of our bodies when they encounter problems (Thomas and Johnson, 2000; Williams and Bendelow, 1998); in this view, pain is the only somatic experience that provokes awareness of our embodied selves. I might suggest instead that that what pain provokes is the awareness of the *instability* of the phenomenological body; "When the body, like my body ... is no longer consistent over time ... when something that meant one thing in April may have an entirely different meaning in May, then it is hard to rely on the stability - and therefore the truth - of the body" (Butler and Rosenblum, 1991, pp. 136–137). We give meaning to pain, and we objectify it, because we cannot but do otherwise; pain cannot be understood as raw physicality without meaning, because in understanding it thusly *we give it meaning*, even if that meaning is that it is meaningless. "The physicality of the experience of human pain is ... imbued with meaning, and cannot be approached from within a paradigm that splits the objective body from the subjective experiencer of that body" (Grace and MacBride-Stewart, 2010, pp. 153–154).

Pain, Suffering, and Religious Belief.

There is, of course, an exception to the concept that pain is inexpressible, violent, and overwhelmingly negative – the rare times when pain is creative. Within medicine, and the various discourses of health, the exceptions are pain in childbirth, and pain resulting from exercise; both situate pain in terms of a temporary experience that must be gone through before the resulting reward. This discourse, particularly around pain in competitive exercise, situates pain as a sign of our own abilities or limitations – but particularly in terms of ‘pushing through;’ this discourse is profoundly ableist, equating pain with weakness, and with not ‘pushing yourself’ regarded as ‘giving up’ – when those of us with chronic pain and fatigue may view ‘pushing yourself’ as a sign of both the ableist nature of the pace of modern life⁵⁵ (Wendell, 1996) or as a need to stop and rest (Kafer, 2013). This discourse, while overlapping with discourses of health and risk, overlaps significantly with discourses of pain and suffering in spirituality and religion.

Within spiritual and religious discourses, pain is often conflated with suffering; Schwartz and Lutfiyya’s (2012) discourse analysis demonstrates that, for many, pain is a central premise of suffering. Across the major religions (Islam, Christianity, Judaism,

⁵⁵ See p.73 for more on pace of life, time, and ableism.

Buddhism and Hinduism), suffering, including experiencing physical or mental pain, is cast as part of life, albeit for varying reasons. Judaism and Christianity's discourses around the reasons for suffering are broadly similar – with the details varying between religion and between the various strands of belief or doctrine – with both religions viewing suffering as a punishment for sin, as a form of corrective education, and to deepen an individual's relationship with their god (Schwartz and Lutfiyya, 2012). Christianity, in addition, sees suffering and pain as purification, resulting from original sin – especially in the case of childbirth (Schwartz and Lutfiyya, 2012). Suffering as a result of individual sin, in both Judaism and Christianity, originates in interpretation of the Hebrew bible.⁵⁶ Within Islam, illness, disability, and suffering are viewed as the shameful result of deviance and sin (Hamdar, 2014), as well as – like in Judaism and Christianity – an opportunity for redemption and spiritual development.

Buddhism, in contrast, has one root explanation for suffering; it is the result of as selfish attachment to something, with relief to come from 'letting go' of worldly possessions and needs (Schwartz and Lutfiyya, 2012). Within Buddhism, suffering and pain is a part of life, with spiritual growth often equated with recovery from illness; in this way, suffering (and pain) is a spiritual issue as well as a medical one. "Buddhism suggests that suffering decreases and healing increases when we let go of wanting

⁵⁶ And therefore in the Old Testament.

things to be different from how they are and instead move towards an acceptance of what is available in the present moment" (Schumm and Stoltzfus, 2007, p. 11). In a medical/psychological setting, this is echoed in the mindfulness therapy offered to people with chronic pain, as well as some mental health issues; mindfulness has its roots in Buddhism.

This belief of the source of suffering parallels with the Judaeo-Christian and Islamic discourse of suffering as a form of teaching the sufferer, or deepening their faith. In Christianity, with varying levels between the various branches, there is "the pervasive ... suspicion that sickness is somehow merited by sin and that a first step towards healing is the recognition of one's own guilt ... In Christianity, as in Buddhism, healing is not marked by the absence of physical turmoil, but by the presence of resiliency and the quest to perform embodied acts of loving kindness" (Schumm and Stoltzfus, 2007, p. 14).

The discourses in Christianity, Judaism, and Buddhism all parallel the cultural discourse in which pain and suffering is a source of growth (Bendelow and Williams, 1995), or, in terms of risk culture, the result of a particular behaviour or inaction. Whether the discourses involved are based in religion or not – and in many cases I would argue that it doesn't matter, as a sociocultural discourse has influence

regardless of whether or not it is explicitly religious, or acting outside a religious setting – ignorance of the actual experience of living with pain is the norm, with laypeople often unaware of what pain management might involve (Schwartz and Lutfiyya, 2012; Wendell, 1996). This, together with the aforementioned discourses, results in people with disabilities, impairments, and chronic illnesses “[carrying] a spiritual burden resulting from a religious and social milieu that is suspicious of their spiritual condition. There is a persistent insinuation that chronic illness and disability somehow involve merited suffering (i.e. lesson to learn or result of sin)” (Schumm and Stoltzfus, 2007, p. 10).

In modern discourses, medical, social or religious, suffering is often presented as incompatible, not just with being normal, but with being *human*. It is impossible, according to these discourses, to develop or continue as a ‘normal’ or complete person, or a society as a whole, when you are suffering⁵⁷ (Schwartz and Lutfiyya, 2012); suffering reduces people to animals, and counters the influence of (Western) ‘civilisation’. However, discussing what makes pain *pain*, and how we understand pain, problematises a broad range of discourses and social constructs, and limiting the discussion of loss, pain, illness, fatigue, depression and negativity limits the futures imaginable and the discourses available (Crow, 1996; Kafer, 2013).

⁵⁷ The exception being the productive emotional suffering of ‘the artist.’

Medicine and Pain

To examine the medicalization of pain alongside medicine as a form of knowledge, we can take a Foucauldian approach, positioning knowledge as a form of power, and the clinic and medical systems as forms of government and control. Tremain, when applying such an approach to disability, writes that “during the past two centuries, in particular, a vast apparatus, erected to secure the well-being of the general population, has caused the contemporary disabled subject to emerge into discourse and social existence”⁵⁸ (Tremain, 2005, pp. 5–6). This particular apparatus relies on a Cartesian dualism; the divide between reason and madness, sensation and rationality, self and other, and of course, sick and healthy, dead and alive (Turner, 1996).

Despite this dead/alive divide, it is the corpse that is at the centre of medical knowledge, as Foucault points out in *Birth of The Clinic* (1973). As Leder (1990) observes, this contributes to the conception of the body as machinic, with fixable, replaceable parts (Grosz, 1994; Morris, 1991), where “the patient's own experience and subjective voice become inessential to the medical encounter” (Leder, 1990, pp.

⁵⁸ See p.40 for more on the medicalisation of disability and p.118 for how this fits into rehabilitation.

146–148). Wendell, drawing on this approach, writes that "the cognitive authority of medicine in the doctor-patient encounter gives far more weight to the doctor's metaphysical stance, undermining the epistemic confidence of patients in the importance of their bodily experience" (Wendell, 1996, p. 12). The positioning of the doctor as knowing, and the patient as unknowing, is supported by the process of becoming a subject of the medical gaze, where, far "from being a locus of self, patients' bodies are transformed into objects of scrutiny, organs in a sack of flesh" (Young, 1997, pp. 11–12). This is echoed in Jain's exploration of cancer in the United States, which opens with an account of objectification at the hands of medical knowledge; "My flesh had become the pathology report - portioned, sliced, flattened onto slides, observed, categorized, and finally rendered into this emailable document" (Jain, 2013, p. 3); in Jain's experience, the patient becomes an object that is incapable of knowledge, which only the medical gaze - properly trained and properly objective - can truly understand.

The original medical theory of pain, Specificity Theory, is the model of pain pathways found in schoolbooks, rooted in the writing of Descartes, with pain receptors, neurons, and the pain centre in the brain receiving signals (Boddice, 2015; Morris, 1991). Specificity Theory primarily focuses on the sensory aspects of pain, where "real' pain ... means physical pain, anchored in visible tissue damage" (Williams and

Bendelow, 1998, p. 157); this mind/body dualism dominated medical theories on pain (Morris, 1991), and although it has been added to in the second half of the 20th century, it continues to dominate mainstream medical knowledge. Bendelow and Williams outline these developments, starting with Gate Control Theory, first published in 1984 (Bendelow and Williams, 1995), which stated that psychological and cognitive variables influence pain perception and response. Developed a couple of years later, Bates' Bio-Cultural Model (cited in Bendelow, 1993) built on earlier work on the cultural factors involved in pain thresholds (Zborowski, 1952),⁵⁹ and added sociocultural factors to the original psychological and cognitive variables, and acknowledged that "social comparison and social learning within ethno-cultural situations" (Bendelow, 1993, p. 275) influenced how pain was perceived by individuals, alongside factors such as prior experiences of pain, anxiety, and the attention paid to the injury the time. However, as Boddice points out, "even though [theories of pain] began to change in the 1960s, we are essentially still living with [Descartes'] dualism in the way medicine is practiced ... Pick up a standard medical text book on pain and you will still find, as a sort of rhetorical Cartesian hangover, a tendency to label nerves that detect *injury* as *pain* detectors, which send *pain* signals to the brain. Such rhetorical slippages have been unsupported since 1965, but they persist and they continue to affect medical practice" (Boddice, 2015 italics original).

⁵⁹ See p.84.

The Cartesian mind-body binary on which the medical conception of pain is built neglects the emotional aspect of pain (Bendelow, 1993; Bendelow and Williams, 1995; Boddice, 2015; Williams and Bendelow, 1998); mental pain, and subsequently any pain thought to have a mental aspect is stigmatised in terms of how it is perceived and treated.⁶⁰

The development of theories that acknowledge the role of emotion and social factors, in the view of Conrad and Munoz (2010), allows room for pain management strategies as second-string alternatives to outright elimination, which includes the integration of complementary and alternative medicine within a multidisciplinary approach to treatment and management. However, despite this apparent consideration for the role of the mind in managing pain, Gate Control Theory, like the wider biomedical approach, is focused on somatic pain alone – and does not give much room to pain that is dismissed under the label ‘psychosomatic,’ or give much in terms of assistance to those with chronic pain (Thomas and Johnson, 2000). As Bendelow and Williams wrote, the primary issue, once pain has been divided into ‘physical’ and ‘mental,’ is

⁶⁰ Arguments abound as to whether or not chronic pain has a mental component – something that is frequently resisted by people with chronic pain-related illnesses, who see parcelling chronic pain off to psychiatry and psychotherapy as a way of either dismissing their experiences as “all in the mind” (and therefore ‘imaginary’), or as avoiding admitting that the medical community is not omniscient.

that “[whereas] physiological specialisation for pain sensations can be identified, in that neurons in the nervous system are specialized to conduct patterns of nerve impulses that can be recorded and displayed, psychological specificity cannot be demonstrated in the same way. No neurons in the somatic projection system are indisputably linked to a single, specific psychological experience. Consequently there is no satisfactory definition which can encompass the diversity of perceptions [of pain]” (Bendelow and Williams, 1995, p. 142). More recent work, using MRI scans of brain activity, have shown that social and emotional pain has similar patterns of brain activity to physical pain (Eisenberger, 2012; Gunaratnam, 2014), leading to the potential for greater consideration to be given to the impact of non-physical violence – including social exclusion and marginalisation – on bodies.

If we take Scarry’s view that it is only “with the best effort of sustained attention” (Scarry, 1985, p. 4) that we can grasp the merest shadow of understanding, then it is only through personal experience of chronic pain that we can truly know what chronic pain is – and yet we seek to understand through narratives of that pain (Grace and MacBride-Stewart, 2010). Contrary to this the medicalization (and therefore the institutionalisation) of pain creates pain as a pathology, and therefore seeking or even accepting pain is deviant behaviour (Best, 2007) – and thus further reinforces the barrier between medic and patient, knower and unknowing. In this discourse pain is

equated with violence (Deckha, 2011); in medical discourse, violence becomes injury or illness – but the external cause remains. The contexts and meanings ascribed to pain within this discourse are relatively limited, and assumes that the reasons for experiencing pain – or describing an experience as painful – are equally limited. In medicine, seeking to understand pain is only useful insofar as a *cause* is sought, and pain is only useful for indicating that something else is wrong. Medicalization “[encourages] individuals to interpret pain as ‘meaningless.’ In medical discourse, pain is understood as a symptom, indicated by the process at work, but in itself of no meaning. While acute pain... serves the process of protecting us, chronic pain serves no obvious purpose” (Best, 2007, p. 168). This reduction of pain to a symptom limits pain to the medical, and both Morris (1991) and Illich (1995) have posited that this medicalisation of pain has led to a loss of significance, of understanding – and thus made pain more of a problem; as Morris explains, "medicine unintentionally but implicitly depersonalises pain by enfoldng it within its machinery of high-tech prowess. It removes its quirky humanness and encourages us to forget that pain is not identical with illness." (Morris, 1991, p. 174). Medicalisation also places the control and treatment of pain solely within the medical sphere, devaluing and dismissing alternatives - or consigning them to the purely psychological.

Pain is not, however, always viewed as negative,⁶¹ even within the medical/institutional discourse; “it could be seen as a sign of health, having a 'signal function' by providing a system of warning the body, and could even be perceived ... as being productive, as in successful childbirth. [In Bendelow’s study, positive] qualities of pain perception were associated with acute, short-lived, invariably physical aspects, although [there was also] the notion that character could be 'strengthened' by having to cope with emotional hurts. A central issue was that of control, linked to having knowledge and information, the lack of which gave rise to a sense of powerlessness. The more pain was associated with being chronic and terminal, the more negatively it was perceived and was inextricably linked with depression, poor self-esteem and mental illness" (Bendelow, 1993, pp. 283–284). Within this discourse, acute pain can be cast as positive in terms of its *productivity*; in other words, as long as the experience of pain itself remains negative and painful, it can be part of a wider positive event, or achieve a measure of usefulness that can construct the ability to perceive pain as positive.

More recently, a further medicalizing discourse has taken a foothold, where pain is a medical issue in and of itself – requiring holistic treatment, rather than straightforward suppression, while the underlying cause is cured (Conrad and Muñoz,

⁶¹ See p.92.

2010). Medicalization can present pain as a subject of medical-scientific research, resulting in greater support for patients with chronic pain – however, Conrad and Munoz’s (2010) optimism may be misplaced, or at least a little early in their assessment of the potential resources. As Wendell (Wendell, 1996) observes, somewhat wryly, doctors and medics don’t like to admit when they don’t know something – as a result of what she aptly describes as a hero complex – and therefore a person presenting with chronic pain (or other symptoms) that cannot be explained or cured are a problem, presenting as they do a challenge to the omniscience of the medical institution – which can result in dismissal of their pain, or active negativity or abandonment when doctors cannot ‘fix’ a person (Wendell, 1996).

Furthermore, the positioning of doctors as sole holders of knowledge about bodies rather obviously destabilises the patient as being in a position of self-knowledge; when their doctor announces that there is “nothing wrong” or that their pain is “all in your head,” people can cease to believe *themselves*, and begin to accept an incorrect judgement of psychosomatic illness, or dismissal without a proper diagnosis. For “[many] people whose disabling physical conditions were not diagnosed for months or years [who] describe increasing worries about their own sanity and judgement ... part of the relief of receiving a diagnosis, any diagnosis, is the confirmation by medical authority that they are not 'crazy' after all” (Wendell, 1996, p. 125), especially in

situations where medicine, and the doctor, are figures of ultimate authority, and when medical discourses control how we can interpret our own bodily sensation.

The "moral dimension of beliefs and practices surrounding different health states" (Bury, 1991, p. 456) results in stigma experienced by people with chronic pain, as well as people with other diagnoses (Illich, 1995). Despite the figures of incidence of chronic pain⁶², the medical approach to illness and disability universalises experiences – expecting illness and disability to fit particular patterns of behaviour and progress⁶³ (Wendell, 1996); for many, the labels ‘chronic fatigue’, ‘fibromyalgia’, or simply ‘chronic pain’ can be seen as a sort of diagnostic dustbin – where the diagnosis is more often seen as an umbrella term, a shorthand for ‘we don’t know what to do with you’; for participants in Nielsen and Fernandez’s study into patient experiences, "the lack of a culturally condoned, straightforward label for their condition, as is available for many other health states, contributed to participants being alternatively, if not explicitly, labelled as somehow different or difficult" (Nielsen and Fernandez, 2010, p. 45), with this stigma leading to the under-treatment or dismissal Wendell observed (1996). Patsavas draws attention to medics who identify 'risk factors' of chronic pain

⁶² See p.12.

⁶³ See p.36 for more on the paradigmatic disabled person, and p.118 on rehabilitation.

that "read more like character flaws than biological markers" (Patsavas, 2014, p. 210); the conflation of chronic pain with the moral state of a 'sufferer' is firmly embedded in culture - both in terms of religious understanding⁶⁴ and non-religious discourses of risk and health⁶⁵.

It is not just the patients' perceptions of their experiences that indicate this stigma; "in a study of 268 registered nurses, the chronic pain sufferer was negatively stereotyped and judged to have less intense suffering than an individual with acute pain" (Thomas and Johnson, 2000, p. 684). The stigmatisation of people in chronic pain by medics and healthcare professionals can have very real effects, such as when Morris explains that "American doctors regularly refuse to prescribe effective doses of narcotic painkillers to dying patients [with terminal cancer] on the grounds that the patients might become addicted. The treatment of cancer pain, clearly, is still not based solely on scientific fact but draws on ignorance, fear, prejudice, and on an invisible, unacknowledged moral codes expressing half-baked notions about the evil of drugs and the duty to bear affliction" (Morris, 1991, p. 192). This stigmatising of people with

⁶⁴ See p.92.

⁶⁵ See p.123.

chronic pain comes, in part, from the discourse of health and risk⁶⁶; this discourse creates a victim-blaming approach to illness, placing the onus for not preventing their illness – or dealing with it in the ‘correct’ way – on the ill person. People who are perceived as having done something to cause, or not done something to prevent, their illness, are treated less sympathetically, and stigmatised (Bendelow, 2006), by medical professionals, carers, other people, and even other people with the self-same illness or impairment; as Richardson observes, “as members of a society which shares a cultural understanding of pain, sufferers may be both the subjects of, and makers of, ‘misguided inferences’ about pain and its legitimacy” (Richardson, 2005, p. 36).

This stigma is gendered and racialised; women with chronic pain report feeling greater stigma, and being taken less seriously when they seek medical help (Bendelow, 1993; Hoffman and Tarzian, 2001). Bendelow considers that this may well be tied to the societal belief that women tolerate pain better – they have ‘higher pain thresholds’ – but that they ‘give in’ more easily to pain than men, who are able to ‘push through it’ (Bendelow, 1993). For women of colour, this effect is added to by the perception – rooted in 18th and 19th century ‘scientific’ discourse that dehumanised non-white people, women, and children (Morris, 1991) – that black and brown bodies are ‘less sensitive’ to pain, and black women, in particular, are more able to cope with high

⁶⁶ See p.123 and p.126.

levels of pain without help (Hoffman *et al.*, 2016; Staton *et al.*, 2007; Trawalter *et al.*, 2014). This is echoed in discourses positioning black athletes as less civilised and more animal-like than their white counterparts (Trawalter *et al.*, 2014), less sensitive to pain and more capable of ‘powering through.’

To take apart these misguided inferences the experiences of people with chronic pain, and their subjective voices, need to be heard – to shout over the stigma of speaking up about pain. As has been noted, "perhaps the main problem for those with chronic pain is that they are bereft of adequate cultural resources for organising their experience" (Bendelow and Williams, 1995; Wendell, 1996; Williams and Bendelow, 1998, p. 163). However, because discourses tell us that pain is either meaningless or inexpressible, talking about pain, describing the experience of pain, becomes difficult – even before the stigma of talking about pain comes into play. I would argue that, while others must take my word for it when I discuss my pain, we do not express ourselves in isolation – we have referential experiences, and cultural resources, on which to draw up on when an unfamiliar experience is described to us. We don’t seem to have a problem appreciating *positive* experiences, after all.

Thomas and Johnson write that previous research into experiences with chronic pain reports that “chronic pain patients described their experiences as an individualized

dialogic process between themselves and their painful condition. Their Lebenswelt (life world) was shrunken and their freedom greatly constricted. The pain set up a wall or barrier that separated them from other people. Pain dominated their consciousness" (Thomas and Johnson, 2000, p. 689). However, despite the dominance of pain, the same participants reported self-segregating themselves because they felt that others would judge them negatively and treat them differently - and of a need to hide their pain because of a lack of social acceptance - this leads into a cycle of isolation (Thomas and Johnson, 2000). It is the social effects of talking about pain – because we don't want to imagine ourselves in that position, perhaps, because pain must be violent and negative – that have as much impact on the lives of people in pain as the pain itself does.

Bendelow and Williams (1995) viewed chronic pain as needing a cause to prevent despair and isolation. I would contend that it is the dismissal of pain as either *all in your head* or *all your own fault*, and of chronic pain without visible cause as somehow less significant than acute pain, or pain with a visible cause that leads to isolation, as Thomas and Johnson (2000) observe, rather than solely the pain itself. For some people with chronic pain, the combination of a lack of a visible cause and the duration of being in pain, causes a sense of deligitimation, of feeling like the fakers and malingerers social discourses paints us (Richardson, 2005) – and expressing pain or

fatigue to others can exacerbate this, while the omnipresent nature of chronic pain created and continually reinforced a sense of isolation and estrangement from society" (Nielsen and Fernandez, 2010, p. 47) – precisely because of the discourse that our pain cannot be understood by others.

This lack of knowledge around pain, and the lack of ability to express pain, in Wendell's view, leads to a fear of experiencing pain – increased by the myth of control, and being able to control your body; "the fear of pain is also expressed or displaced as a fear of people in pain, which often isolates those with painful disabilities" (Wendell, 1996, p. 109). This isolation, while rooted in others' fear of pain, increases the impact of suffering that results from a loss of autonomy (which is often equated with personhood, where being economically productive is reliant on being autonomous (Kafer, 2013; McRuer, 2006)), and a loss of dignity, itself a reflection of a value on perceived independence (Kafer, 2013; Schwartz and Lutfiyya, 2012; Wendell, 1996) – all of these, however, are based in ableist assumptions of what is needed to be 'happy' and, above all, 'normal.'

Impairment versus Disability

The difference between impairment and disability is both semantic and central to understandings of disability, particularly when understanding is based in the social model or medical model of disability.⁶⁷ The medical model dominates in how impairment is discussed (Turner, 2001), and medical understandings position impairment as a lack or loss – situating a loss at the core of disability, producing a hierarchical scale, with those ‘closest’ to ‘normal’ (with the least ‘loss’) at the top, while those perceived as having ‘lost’ the most function (regardless of whether or not that ‘loss’ was acquired or simply one of ‘lost potential’) at the bottom. This means, as Overboe observes, that “the arbitrary split between disability and impairment privileges the rationally controlled disabled person, thus creating a personae that fundamentally is a facsimile of the ‘able’ personae and supplants the vivacity of a disabled life expressed through impairment” (Overboe, 2012, p. 115). To Overboe’s rationally controlled disabled person, I would elaborate that this requires a fixed, unvarying impairment, with predictable and straightforward needs – the disabled people most easily embraced through neoliberal inclusivity projects (Goodley, 2014; Mitchell and Snyder, 2015).

⁶⁷ See p.40 on the medical model, and p.46 on the social model.

Impairment is largely ignored in the social model of disability,⁶⁸ which is primarily concerned with how disability is constructed on impairment – impairment, and the body, instead remains the concern of medicine. Discursive constructions of impairment reflect, maintain, and legitimize normality (Tremain, 2005), while constructions of normal bodies and somatic responses – and to follow this argument, then pain is itself – are discursive productions, “cultural artefact[s] ... in need of interpretation” (Best, 2007, p. 168). If the body itself is considered to be socially constructed, then impairment is “both an experience and a discursive construction” (Hughes and Paterson, 1997, p. 329), and there is a “need to construct an analysis of impairment that assumes our somatic sensations, including pain, are discursively constructed” (Best, 2007, p. 163). This is in contrast to understandings that position pain - in particular - as inexpressible and beyond language (Scarry, 1985); somatic sensations are assumed to be outside of linguistic constraint or understanding, and thus beyond discursive construction.

This framing of pain as universal and beyond discursive construction may go some way to explaining why chronic pain and chronic illness, in particular, have been objected to as impairments resulting in disability by proponents of the social model.⁶⁹ Oliver

⁶⁸ As previously discussed – see p.46.

⁶⁹ See p.46.

(2013, 1996) has argued that because pain is universal, and everyone, able and disabled alike, experiences pain at some point, pain is not a disability,⁷⁰ but a medical problem alone. Pain is in effect *too* normal – too much a part of normal life. For de Wolfe (2002), critiquing this viewpoint, pain is an ‘embarrassment’ that disability rights activists and some disability studies academics do not always want to engage with, and therefore “this reluctance relegates to the realm of the private, both conceptually and materially, those whose suffering cannot be relieved by either medical intervention or social change” (de Wolfe, 2002, pp. 255–256). While de Wolfe’s equation of pain with suffering is problematic, the argument instead demonstrates that a purely interactionist social model view of disability silences and isolates experiences of chronic illness and chronic pain.

Chronic illness is harder to separate into impairment and disability using a social model understanding, partly because illness is so firmly rooted in medicine, even more so than some widespread conceptions of disability, and partly because chronic illness is understood as an individual – rather than collective – experience, perhaps even an individual failure of self-control and self-regulation.⁷¹ Chronic pain, too, is difficult to grasp in terms of social construction, because, as Morris (1996) and Wendell (1996)

⁷⁰ Oliver has reportedly since changed his mind.

⁷¹ See p.123 on control.

have both pointed out, disability comes in when it comes to how normal concepts of time, function, and sensation are constructed – it is much more straightforward to grasp the concept of disability when it comes to mobility than when it comes to fatigue or pain.

Pain is also ignored by those disability rights activists and disability studies academics who focus solely on disability as a positive identity, who side-line engagement with vulnerability, fatigue, and pain. This problematic viewpoint is neatly encapsulated by Siebers, writing that “physical pain is highly individualistic, unpredictable, and raw as reality. It pits the mind against the body in ways that makes the opposition between thought and ideology in most current body theory seem trivial. It offers few resources for resisting ideological constructions of masculinity and femininity, the erotic monopoly of the genitals, the violence of the ego, or the power of capital. Pain is not a friend to humanity. It is not a secret resource for political change. It is not a well of delight for the individual. Theories that encourage these interpretations are not only unrealistic about pain; they contribute to an ideology of ability that marginalizes people with disabilities and makes their stories of suffering and victimisation both politically impotent and difficult to believe” (Siebers, 2006, p. 178). Of course, I both agree and disagree with Siebers – while pain is highly individualistic, it is also socially constructed; pain does exactly what he says it does not, in that pain can be a delight

for the individual, and as BDSM practitioners have demonstrated, it can be a part of resisting power structures and exploring eroticism and pleasure beyond genital contact⁷². I would contest, with this research, that exploring how pain is socially constructed as well as experienced reveals much that resists and challenges ableism, offering a critique of the understanding of pain as always, exclusively, negative.

Pain as Disability

Pain is considered a largely medical or psychological problem (Conrad and Muñoz, 2010), due to the perception that pain is either sensory, and therefore needs to be treated medically (Seymour, 1998), or is psychological and therefore needs to be treated by psychologists. This, as has been pointed out⁷³, makes it difficult to consider pain in itself as a disability, or as a part of disability, when a great deal of the work done by disabled people has been to distance themselves from medicine and medicalisation, and there is frequently an assumption that wanting medical assistance or treatment (or even a cure for others in the future, if not for oneself (Wendell, 1996)) is the same as accepting the medical model (Kafer, 2013). However, much like

⁷² See p.158 for more on pain and BDSM.

⁷³ See p.111.

other impairments, pain is considered as pathological, as a deviance from norms (Best, 2007), especially when it continues over an abnormal length of time – when acute pain becomes chronic. Living with chronic pain can parallel the experiences of disabled people, and in exploring those parallels it becomes possible to consider chronic pain as a disability in itself.

There is a stigma around being in chronic pain, particularly chronic pain with no identifiable cause, which frequently leads to under-treatment of that pain, such as the under-prescription or withholding of painkillers (Morris, 1991; Nielsen and Fernandez, 2010), just as other diagnoses can lead to aspects of impairment/disability being downplayed or ignored by medical care. Symptoms are a key part of medicine, as the physical manifestations of disease, but, if we take Foucault's (1973) reading that little bit further, there tends to be the assumption that the symptoms themselves do not need treating, only the underlying disease – and therefore if the symptoms do not lead to a clearly identifiable disease with a straightforward treatment, those symptoms can go untreated, just as if medicine cannot cure the underlying impairment, then no further care is needed. There is also the problem thrown up by the problems many people in pain have with communicating pain⁷⁴, either due to the limits of language in adequately communicating pain, or due to the unwillingness of

⁷⁴ See p.88.

listeners to hear about pain - especially pain that has already been diagnosed as 'untreatable' or 'without cause.'

Chronic pain without an identifiable cause has no "culturally conditioned, straightforward label, as is available for many other health states, [which] contributed to [participants in Nielsen's study] being alternatively, if not explicitly, labelled as somehow different or difficult" (Nielsen and Fernandez, 2010, p. 45). This labelling of people with chronic pain as *different* or *difficult* is a familiar one to disabled people, often given such labels when requesting reasonable adjustments or calling for greater attention to be given to their rights or needs. An unnamed illness disrupts the whole discourse of medicine itself; illness only becomes visible once it is named, because once it is named it is *manageable* and *curable*. At the same time, because diagnosis is so often used to police access to assistance, living without a diagnosis can often be experienced as disabling specifically because it leaves one without access to the help that comes in the form of community groups and spaces of shared experience. Invisible disabilities – ones requiring no obvious aid, like a walking stick, or that do not mark the body as somehow 'abnormal' – are often assumed to be non-existent; like disabled people with invisible disabilities, people living with chronic pain must somehow 'prove' their disability (Richardson, 2005), not just for access to medical care, but also for social recognition.

The lack of cultural resources for understanding or organising experiences of chronic pain (Nielsen and Fernandez, 2010; Williams and Bendelow, 1998) are often expressed as a social pressure not to talk about chronic pain, particularly for women, with the gendered discourse of the whining, weak, hysterical woman playing a key part in this silencing (Richardson, 2005). “This pressure may be exacerbated for women in cultures which admire the ‘restitution narrative’ (Frank, 1995) in which people are ill, recover, and ‘return to normal’, or in which certain illnesses are seen as discrediting and hence to be hidden ... Cultural perceptions that women have a greater resilience to pain on a ‘day-to-day’ basis leads to the idea that women’s pain does not therefore need to be taken seriously” (Bendelow, 1993). Women therefore face a dual dilemma that expression of their pain is necessary if they want to be taken seriously, but, at the same time, this remains socially undesirable” (Richardson, 2005, p. 37). This parallels with the experience of disabled people, who have not returned to, or have never been, ‘normal,’ and whose experiences are only rarely represented.

Chronic pain is often experienced as isolating (de Wolfe, 2002; Nielsen and Fernandez, 2010), partly through a lack of understanding from others (Morris, 1991), and even more so as a result of this ongoing pressure towards silence (Richardson, 2005), particularly in cultures where illness and disability are constructed as private

experiences, not suitable to be seen or expressed in public (Wendell, 1996). Wendell observes that “the inclination to keep those who are more than temporarily ill out of the stream of work and social activity is based as much on ignorance and prejudice as is the inclination to keep other people with disabilities hidden in the private realm” (Wendell, 1996, p. 20). Addressing disability with a more crip approach creates space within disability for chronic pain and chronic illness, arguing that the issue of “dividing experience into segments, of denying its fluidity, and of specifying a stable disabled identity ... [is unworkable when] disabled people allude to a complex existence that occupies the space *between* health and illness, disability and normality” (de Wolfe, 2002, p. 258 italics original).

Rehabilitation and Medical Discourses

Within medical discourses, pain – either acute or chronic – signifies illness or injury; there is an assumption that there is a straight line from the symptoms of illness, to diagnosis, to cure (Snyder, 2004). This discourse of a stepwise, problem-solving approach has filtered from medicine to wider social discourses – we go to the doctor when we are ill, and we expect to be told what is wrong with us (even when we think we know beforehand), and we will receive a cure; this ties to what Frank (1995) calls the ‘restitution narrative’ – once the diagnosis and subsequent cure are received from

the proper authorities, we ‘get better’, and return to normal once again, having been healed by whatever pill or potion the doctor has prescribed. In this discourse, as through much of the psychological and medical discourses, there is a conflation of cure and healing (Barker and Langdridge, 2009); this conflation extends into discourses around long-term or chronic illness, and disability; all of which are positioned as requiring *curing*, as problems to be solved.

Particularly following an injury⁷⁵ (this injury is usually assumed to be physical, although there are similar discourses of mental injury following traumatic events, such as bereavement), we go through a period of healing – it is this process of healing that ‘cures’ us; the most familiar might be being told to ‘keep your weight off it for a few days’ following a twisted ankle, or physiotherapy following a broken bone. Once this healing period is over, the cure is complete and we are ‘normal’ again; the more traumatic the injury, the longer the healing period – but this period must have an ending. In some cases, we go through part, or all, of this healing period under the care and gaze of professional rehabilitators – doctors, physiotherapists, nurses, and aides. The length of the healing period can be predicted – and prescribed – by these professionals; for a painful injury, the prediction of a particular length of time reassures the person that their pain will end, and reassures them that normality will

⁷⁵ See p.81 as well.

be regained.

Following injury, the body is given over to medical professionals, and each stage of healing is medicalized. For many, this can be experienced as a loss – a loss of self-control and self-knowledge, of power over your own body (Young, 1997); replaced by the power and knowledge of medical professionals and care workers (on whom the newly injured person is dependant); medical personnel can control how much input patients have, with a 'doctor knows best' attitude prevalent⁷⁶, especially when it comes to setting and achieving "recovery milestones" (Sullivan, 2005). While pain can be – and frequently is – a part of this rehabilitation and healing process, the cessation of pain is expected once the process is over, and once the injured body is rehabilitated.

This rehabilitation and healing process is conceptualised by Turner (2001) as a rebuilding process, "[involving a] refashioning [of] the self. This remaking is not merely a discursive process; it involves, following Merleau-Ponty, the reconstruction of the lived, sensual body ... [It] also takes place within the professional 'gaze' of rehabilitation which holds out the typically false promise of normalization, that is, the

⁷⁶ See p.122 and p.128.

production of a socially 'normal' body - young, athletic, and sexual. It is not enough to return to society via rehabilitation; the rehabilitated body has to be discursively normal" (Turner, 2001, p. 258) in order to be fully cured. It is interesting to note here that Turner doesn't even mention being pain-free as a condition of normality; being pain-free is such a key part of having a normal body that it is immediately assumed that the two are one and the same; being without pain is rendered invisible by its very position as normal. This process of achieving normality, at least as far as the body is concerned, is also about rendering the body docile to systems of power and government (Sullivan, 2005); the body in pain is not a docile body, but at least it does not disturb others, unless the body speaks and the experience of pain is expressed. Because the body-not-in-pain is so normal, so invisible, bodies are assumed to be bodies-not-in-pain until they are revealed as otherwise, especially when those bodies have no other outward signifiers of disability/impairment. Through shaming and stigma, people who live with chronic pain learn not to talk of their pain,⁷⁷ to become outwardly docile-normal bodies, to be civilised.

Normality, just like medical knowledge, is a construction; it has its roots, at least in terms of modern concepts of "normal" in the development of 'civilising' modes of biopower and government (Foucault, 1973; Hughes, 2012; Tremain, 2005). The

⁷⁷ See pp. 88, 107, and 117 on speaking about pain.

division between “normal” and “abnormal” is a constantly-shifting imaginary line, with a very solid, tangible impact. During the growth of the asylum, disability and moral perversions (homosexuality, or having multiple children out of wedlock, for example) were lumped in together (Carlson, 2005; Foucault, 1973; McRuer, 2006); being diagnosed queer was as crippling as being diagnosed as missing a limb, while “mental retardation” could be applied to huge swathes of the population, as and when required (Carlson, 2005). The medicalization of both disability and queerness took bodily control away from disabled and queer people, and placed it in the hands of doctors – this control has continued to be held by doctors, who are required, through the discourse that casts the holders of medical knowledge as omniscient and all-powerful, to control the bodies of their patients, to heroically save their lives⁷⁸, or at the very least, save them from the illnesses and injuries that beset them, perhaps beyond or in ways against the wishes of the person themselves (Wendell, 1996).

The control of doctors, when it fails, casts blame not on the doctor, but on the ill or injured body – they ‘gave up the fight’ or ‘the injury was too severe,’ or simply ‘didn’t want to get better’ – and therefore on the ill or injured person themselves; control returns immediately to self-control, as “[the] context of healing in [Western] society is a culture that considers controlling one’s body a criterion of full humanity and of

⁷⁸ See p.128.

social acceptability" (Wendell, 1996, p. 98). Wendell (1996) explicitly links the myth of control with the classing of 'inexplicable' illnesses (ME/CFS, fibromyalgia, and so on) as psychosomatic; she doesn't draw on Foucauldian understandings of the clinic and medicine, but identifies similar themes and discourses to those who do - that medicine seeks to exclude those who it cannot cure/control in order to continue the illusion of being omnipotent.

The Controlled Body and Risk

A controlled and controllable body, is, as previously stated, a docile, plastic, and mouldable object, composed of individual parts that are either fixable or replaceable (Grosz, 1994; Williams and Bendelow, 1998). At the same time, "the line between normality and deviance is no longer rigid, or regarded as naturally given; it is shifting and variable ... In today's 'normalization society', normality is no longer considered an immutable, permanent fact of the matter; instead, it is seen as a challenge, as something that can be designed and produced, as a phenomenon that changes with time. Normality is no longer an external constraint that society imposes on its members; it is formed and shaped by acting subjects themselves. The conception of normality that currently prevails could be termed flexible-normalistic" (Waldschmidt, 2005, pp. 191–192). As a result, normality is both compulsory and an idealistic

conception; we can never achieve perfect normality, because it constantly shifts beyond reach of the individual; we must be flexible, but the uncertainty created by this compulsory flexibility within a risk society (McRuer, 2006), has influenced a modern move in individualism from project of the Self to project of the Body; "cognitive rationalism has been replaced by an emphasis on emotionality, sensibility and sensuality" (Turner, 1996, p. 20).

This shift in focus includes an emphasis on *being healthy* – on being in control of one's self, on having a disciplined body; as "health is the accumulative expression of how we 'matter' in our social worlds" (Adelson, 2010, pp. 50–51), there is a moral dimension to health, where ill health, and even the apparent failure to perform control of one's health, becomes a personal failure of self-discipline, and of needing another (the doctor) to control one's body, rather than simply advising on *how* to control it; this echoes the moral dimension of the asylum discourse, where immorality was equated with disability and queerness. Susan Wendell writes of how her illness, ME/CFS, "was for a while described in the media primarily in terms of the symbolic meanings that were created for it in the mid-1980s; it was the 'yuppie flu', a punishment of nature visited upon the ambitious, especially ambitious women ... the mythic descriptions are more exciting and more reassuring to the healthy than the reality" (Wendell, 1996, p. 62). This reassurance is important, tied as it is to a victim-blaming approach that says,

in effect, 'I didn't do/am not doing *that*, so bad things will not happen to me.'

As a part of controlling our bodily selves – which, it should be noted, includes our mental health – we must assess our own risks of contracting illness and change our lifestyles in order to minimise this risk; this results in a discourse that blames the sick person for becoming ill (Williams and Bendelow, 1998)⁷⁹. The risk and moral danger discourses that intertwine with discourses of health are “articulated and expressed ... through public health campaigns and the forms of 'surveillance medicine' they spawn ... risks to health are no longer conceptualised in existing places and spaces, nor in terms of personal hygiene. Instead, the contemporary emphasis on health promotion, lifestyles and the 'green response' to ecological dangers has meant that risks are located everywhere" (Williams and Bendelow, 1998, pp. 70–71) – and as a result, we must be ever-vigilant to existing risk and flexible enough to change when new risks are identified by the appropriate, knowledgeable, authorities. At this point, it is relevant to note that 'being healthy' is firmly tied to ideals of food consumption and exercise –

⁷⁹ Examining this discourse - which equates becoming ill with personal failure - is perhaps at the root of resistance to including chronic illness in disability - disability activists have long sought to distance themselves from both medical discourses and discourses of blame, and illness only reintroduces these (see p.111 for more on this).

which is tied to class and income through access to alternative 'healthy' options⁸⁰ (Williams and Bendelow, 1998); this tying together of class and 'healthy' consumption is often at odds with the poverty that many disabled and chronically ill people live in (Goodley, 2014).

In discourses of 'being healthy,' which Tremain identifies as one of the multiple forms of governmentality (ibid 2005), it is easy to see how the body has itself become a fetishised commodity, with "lifestyle and body planning ... [forming] a normal part of life in post-traditional, reflexive environments. What might at first appear to be a wholesale movement towards the cultivation of bodily appearance is ... on closer inspection, an expression of a much deeper underlying concern to actively control and 'construct' the body through a pluralisation of lifestyle options and choices that reflexive modernity makes possible" (Williams and Bendelow, 1998, p. 74). Having the 'right attitude' towards health and fitness is paralleled by the cosmetic surgery industry (Williams and Bendelow, 1998); being normal – or striving for normality – requires people to perform fitness (or, as McRuer (2006) puts it, athleticism) and health, while being disabled, chronically ill, or in pain can often form major barriers to performing health from the outset. The tendency to refer to such acts of performing

⁸⁰ Organic over non-organic, fresh over frozen, 'homecooked' over 'pre-prepared,' and so on and so forth.

health and fitness as self-care, and hence framing them in terms of a political act, enabling those of us worn down by neoliberalism, capitalism, racism, sexism, ableism, and debility to get back up and carry on while claiming ourselves as important (Ahmed, 2014; Lorde, 1988), ignores that such performances of conspicuous health may, for disabled people or those with impairments, present instead as *work*, or be inaccessible (Sheppard, 2016, p. 20).

Aside from issues of financial resources and environmental accessibility, for many chronically ill and disabled people, the act of self-care itself becomes more complex – either through the need for assistance for basic personal care, or through the simple fact that some people simply require more time and planning to carry out such tasks (Kafer, 2013; Wendell, 1996); “for those who live with chronic fatigue or pain, for example, the present moment must often be measured against the moment to come” (Kafer, 2013, p. 39). The need to perform self-care through conspicuous health – through acts of exercise and ‘healthy’ food consumption, rather than watching children’s cartoons and eating chocolate – presents a further barrier; there is an increasing need for acts of self-care to be recognisable as such to non-disabled others, in order to be acknowledged as such (Sheppard, 2016). At the same time as such barriers are being thrown up, the figure of the athletic super-crip forms another, spectral, barrier – the disabled figure who has ‘overcome’ their disability through

becoming exceptionally good at a particular sport, or completed a particular event, from becoming a Paralympic athlete to climbing Everest (Kafer, 2013; Sumpter, 2012; Young, 2012); the continual message received by chronically ill people and those with mental health or cognitive impairment diagnoses (in particular) is that with the 'right' diet, exercise, or vitamin supplement – along with the right attitude – they will be 'cured,' while their more obviously mobility and visually-impaired peers will be able to overcome their impairments.

Curing Pain

Just as the heroic,⁸¹ knowledgeable, doctor is required to control their patient's body, they are also obliged to 'rescue' them from suffering – where suffering can be broadly defined as pain or illness (Illich, 1995). They must do so through diagnosing the cause of suffering, and then prescribe appropriate cure and rehabilitation, but first they must decide whether or not their patient's suffering is sufficient to merit rescue - whether they need, or are worthy of, treatment and rehabilitation - or if instead they must perform 'healthy' behaviour first, through losing weight or making other 'lifestyle changes.' In this decision-making and diagnostic procedure, the epistemic

⁸¹ See p.122.

experiences of the patient take a backseat to the knowledge of the doctor, who is able to assess the degree of suffering experienced by another with accuracy, thanks to their medical knowledge. Within this discourse, there is the "underlying notion that eliminating the person is acceptable, if that is the only way to eliminate suffering" (Schwartz and Lutfiyya, 2012, p. 29); the doctor's obligation is to end suffering, not to prolong life. The exception to this is the treatment of cancer, where prolonging life is the primary obligation (Jain, 2013).

For many disabled people, familiar with the ableist attitudes expressed in debates surrounding abortion (Kafer, 2013), 'cure' can be seen as an attempt to wipe out disabled people (and being disabled as an *identity* itself), coming from an ableist assumption that the deepest wish of disabled people is to be 'normal', to be able-bodied-minded - together with the assumption that disabled people must be suffering, and their lives must be, in the words of Fiona Kumari Campbell, ontologically intolerable (ibid. 2005). Susan Wendell puts it best, for me, when she writes, "I find that my own resistance to the attitude that I need to be 'cured' in order to be a whole or fully acceptable person infuses my desire for a 'cure' with ambivalence. I want to have more energy and less pain, and to have a more predictable body; about that there is no ambivalence. Moreover, I feel heartsore when I hear about someone else being diagnosed with M.E.; how could I not want a cure for everyone else who suffers

with it? *Yet I cannot wish that I had never contracted M.E., because it has made me a different person, a person I am glad to be, would not want to have missed being, and could not imagine relinquishing, even if I were 'cured'"* (Wendell, 1996, p. 83 italics added). For myself, I see Wendell's wish for a cure for everyone else not as a need to a simplistic cure, but so much as a need for M.E.⁸² to be understood – and recognised in terms of the experiences of those who have it – as well as for chronic illness to be recast as a source of knowledge; the acknowledgement that the lives of disabled people are worth living.

With the use of the term 'chronic,' *time* is important – illness and impairment, especially in the medical field, is described with reference to time, to duration of symptoms, to prognosis, to duration, to onset and to endings (Kafer, 2013). This imposed timescale is reflected in access to medication and assistance – whether it is how long is deemed an acceptable length of time for a paid carer to spend with a disabled person on everyday tasks, to how frequently medication is taken, and how 'regularly' it is used. For many with chronic pain, 'regular' use of pain medication, particularly prescription medication, is understood not on their timescale, but on those who control access to said medication – and regular use of pain medication

⁸² M.E., or Myalgic encephalomyelitis, is also known as chronic fatigue immune dysfunction syndrome (CFIDS), or more commonly, chronic fatigue syndrome (CFS).

leads inexorably to an assumption of dependency or addiction, no matter how 'regular' is defined – and even though that dependency⁸³ may enable the person in pain to function 'normally' (Snyder, 2004). This division between needing and being addicted depends heavily on whether or not pain – or depression, or infection, and so on and so forth – is classed as 'acute' or 'chronic,' just as the movement from acute to chronic indicates when an illness moves into becoming an impairment – when it becomes something other than an illness.

⁸³ And, speaking for myself, it is a dependency; I need to be able to take my pills when I deem myself to be in need, because otherwise I experience a significant decline in my ability to function at a level I deem necessary, because the pain overwhelms everything other than itself.

Chapter Three: Sex

This chapter will explore sex, first in the context of disability – particularly the asexualisation and infantilisation of disabled people – and then some of the more practical issues of engaging in normative activities related to sex, such as flirting and going to nightclubs. It will then move to the topic of pain and sex, exploring social constructions of sex as painful, particularly for women, and the normalisation of painful sex in romance novels and pornography. The medicalisation of painful sex, and pain during sex, will be followed by an exploration of pain in BDSM – a formation that will take us back to the construction of ‘normal’ activity and sensation.

Sex and Disability

Like other disabled people, people living with chronic pain face asexualisation – the assumption that in acquiring disability they have exchanged sexuality and sexual activity for pain. For some who live with chronic pain, sexual dysfunction *can* be a problem – either as a whole or part of their impairment, but, as Verschuren *et al* point out, “sexual dysfunction as a side effect of chronic disease has long been ignored in both research and clinical practice” (Verschuren *et al.*, 2010, p. 153), and such

research and practise that there is overwhelmingly focuses on erectile dysfunction or reproductive problems.

To turn to sex and disability more broadly, as Shildrick points out, the silence in government on sex and disability is effectively “management by nonrecognition” (Shildrick, 2009, p. 55), underpinned by discourses of asexualisation and a desire for disabled people’s sexuality to effectively disappear (Shakespeare *et al.*, 1996). The approaches to disabled people’s sexuality can be broadly divided into two camps: reproduction and asexualisation. Both are medicalised discourses that objectify disabled people, frequently with the “viewpoint of regulating the fertility of the dangerous female, as well as assisting the damaged male to regain his potency” (Waxman Fiduccia, 2000, p. 168); as has already been discussed, the medical model defines disability in terms of lack, and when it comes to sex and sexuality, there is an assumption of abnormality (Shakespeare *et al.*, 1996), and problems – either disabled people have problems with their sex lives, or their sex lives and sexualities are problems in themselves.

The ableist discourse that results in disabled people’s sexuality and sexual activity being cast as always abnormal means that, “even when disabled people are sexually conservative in their own identities, their active sexual expression – if they have one –

may necessarily fall outside of heteronormativity” (Shildrick, 2009, p. 60).

Heteronormativity is not a particularly wide-ranging grouping, with sex-for-pleasure in particular being only heteronormative when the – preferably monogamous couple – are white, heterosexual, able-bodied/minded, young, and conventionally attractive (Tepper, 2000), and having sex that rarely strays beyond the ‘vanilla;’⁸⁴ arguments could be made that this excludes most people from heteronormativity in some way – but if instead it functions as an ideal, this regulation of sexual activity serves to exclude most those who are furthest from the ideal.

The abnormal disabled person,⁸⁵ whose sexuality is a problem, is one who expresses that sexuality, and sexual desire, with a body that ‘should not’ be sexual – that should not be desirable, or capable of reproducing a disabled future⁸⁶ (Kafer, 2013). This fear of disabled people’s reproductive capabilities is heavily gendered, in that it tends to be disabled women’s reproductive capabilities (and sexualities) that are most feared, and also most medicalised. However, this discourse is also impacted by the ‘type’ of

⁸⁴ Heteronormative sex has arguably become more ‘kinky,’ but more in terms of what Newmahr calls “pornonormative” (see p.166).

⁸⁵ See p.59.

⁸⁶ See p.76.

impairment; people with learning disabilities and those with congenital impairments and 'severe' disabilities are more likely to be cast as in need of fertility control, as "although overtly eugenic excesses are relatively uncommon in the contemporary West, the psychic discomfort provoked by manifest differences that undermine cultural normativities is still operative" (Shildrick, 2009, p. 56).

For Tepper, this focus on the reproductive potential of disabled people, and on "a biologically determinate viewpoint of sex as solely the product of reproduction, and reproduction solely the province of the fittest, usually those with access to the full enjoyment of citizenship, has largely served to exclude disabled people. In addition, a social cultural viewpoint of sex as a source of danger leads to the presumed need to protect [disabled people]. Disabled populations are not viewed as acceptable candidates for reproduction or even capable of sex for pleasure. We are viewed as child-like and in need of protection" (Tepper, 2000, p. 285). Asexualisation and infantilisation, accompanied by de-gendering (Shakespeare *et al.*, 1996) is often imposed on disabled people, from a non-disabled, ableist point of view. In this discourse, disability is a medical condition and a tragedy, and therefore as far removed from sex as can possibly be, with the disabled body cast as permanently dependent and childlike, and preferably kept that way through medical intervention (Kafer, 2013) or through the enforcement of 'protective' structures that can act

instead as a removal of choice and personal power. Disabled children frequently receive little to no sex education, particularly if educated at segregated (or 'specialist') schools, and there is an expectation that disabled children will not become sexually active adults (Shakespeare *et al.*, 1996), with information withheld in order not to 'confuse' them, or 'encourage' sexual activity (Rogers, 2009).

For disabled adults, there is the assumption that acquired physical impairment results in a lack of sexual ability, and therefore sexual desire (Shakespeare *et al.*, 1996), with a loss of function equated to loss of sexuality itself (Shildrick, 2009). When disabled people are imagined as sexually active, it is frequently thought that they will only have sex with other disabled people (Crossan and Monaghan, 2013; Shakespeare *et al.*, 1996); disabled people are the only people who should find other disabled people sexually desirable. The positioning of disabled people as childlike and vulnerable further aids in this perception; desiring the/a disabled body is stigmatised and suspect (Kumari Campbell, 2009; Waxman Fiduccia, 2000), with the able bodied/minded person cast as predatory, even paedophilic, preying on vulnerable, innocent, childlike disabled people. For devotees, those who have a sexual attraction to people with specific impairments, besides being cast as predatory (Aguilera, 2000; Kafer, 2012; Solvang, 2007) and exploiting vulnerable disabled people, having their sexual attraction cast as a fetish means that, "reading between the lines, the implication ... is

that someone who would actually be attracted to a person with a disability must be sick” (Aguilera, 2000, p. 258).

For disabled women, “sexist stereotypes of women reinforce prejudices about disability in both cases, dependency, vulnerability, and frailty are the dominant association in patriarchal culture” (Shakespeare *et al.*, 1996, p. 59). This gendered discourse of disability places disabled women as in need of protection – presumably from predatory violence, but also from their own inherently dangerous biology, as the case of Ashley X so clearly demonstrates (Kafer, 2013); disabled women’s bodies are marked as dangerous if they are not forced to be asexual.⁸⁷ For women with acquired disabilities, this can cause conflict in relationships, as anecdotal and “evidence suggests that, in heterosexual contexts, disabled men are more likely to maintain their relationships, while disabled women are more likely to find themselves abandoned by their erstwhile partner” (Shakespeare *et al.*, 1996, p. 95). This is undoubtedly tied to “discourses of women with disabilities as non-gendered, nonsexual, childlike and dependent ... [and therefore] unable to be sexual, spouses, partners or mothers” (Zitzelsberger, 2005, pp. 395–396).

⁸⁷ This is not to say that there are no asexual disabled people – but instead that asexuality is imposed against their will and desires.

For disabled men, “popular notions of disabled masculinity focus obsessively on perceived impotence and lack of manhood” (Shakespeare *et al.*, 1996, p. 97), and in the case of acquired disability, a loss of normative bodily function – particularly when it comes to the ability to get and sustain an erection – is often assumed to be accompanied by a loss of desire (Shildrick, 2009). Disability is positioned as a loss of masculinity, with Shakespeare *et al* (1996) arguing that for many physically disabled men, masculinity must be either adapted or rejected. The “inability to perform gender and sexuality in a way that meets dominant societal expectations is seen as an intrinsic limitation, an ‘unfortunate’ but unavoidable consequence of inhabiting a disabled body” (Rembis, 2010, p. 51), particularly within a medical/tragedy model viewpoint; the standards of heteronormative masculine behaviour cannot be performed by a body fails to meet the standards of heteronormative ableism.⁸⁸ For some men, disability can also act as a ‘release’ from the demands of fulfilling a masculine gender role (Shakespeare *et al.*, 1996), with the presumed inadequacy of deviation from the norm (Tepper, 1999) acting instead as ‘permission’ to explore beyond heteronormative ideals of masculine sexual behaviour – which some disabled men feels gives them an advantage over non-disabled men (Guldin, 2000).

⁸⁸ This does, however, contrast with the discussion around disabled men’s ‘right’ to sexual activity and the employment of sex workers, which we shall come to on p.142.

For men with learning disabilities, the focus is much more upon the need to *control* their sexuality, rather than assist them in regaining some form of masculinity. People with learning disabilities are often positioned as infantile (we will come to infantilisation below), childlike, or even less than fully human – and for men with learning disabilities this means that their sexuality is problematic, or even a dangerous nuisance – dangerous in that they may reproduce (thus passing their disability on to a child), and a nuisance in that it is not properly controlled, but instead a childlike or even inhuman expression of sexual pleasure.

The focus on reproductive potential means that LGBTQ+⁸⁹ people are ignored and made invisible; they are frequently not mentioned by medical studies – less than 1% of public health studies are explicitly about LGBTQ+ people (Boehmer, 2002). LGBTQ+ populations are excluded from concerns around fertility and reproduction, and, like disabled people, there is the “suspicion by majority populations that they cannot, will not, or should not contribute to the future of the human race. They will not reproduce, but if they do, the expectation is that the results will be tainted” (Siebers, 2012, p. 41). This ‘reproductive irrelevance’ means that there is little discussion of LGBTQ+ disabled people’s sexuality or sex lives, beyond aspects around education and control, where their sexuality and sexuality is once again positioned as a problem.

⁸⁹ Lesbian, gay, bisexual, trans, queer, and other gender & sexual minorities.

Disability studies itself has been accused of a heterosexual and heteronormative bias when it comes to sexuality, and of continuing to use binary concepts of gender, sex, and sexuality (Tremain, 2000), treating gender, sex, and sexuality as fixed and natural, rather than sociocultural constructs – this is particularly apparent in aspects of the discipline that assume a medical model position. Greenwell and Hough’s meta-study of articles with keywords or titles including both ‘disability’ and ‘sex,’ published between 2002 and 2006 showed that while 84 articles were published, only 2 mentioned trans as a gender variant, while three-quarters did not include data on sexual orientation of any participants (Greenwall and Hough, 2008). More recently, McRuer and Mollow (2012) that the attention paid to non-heteronormative disabled people has grown – and as crip theory approaches gain popularity, will continue to grow – but research into disability and sexuality remains a niche area, and there is a continued need to move beyond binaries and tolerance (Rembis, 2010).

Inaccessible Sexual Spaces

A range of impairments and disabilities leads to a range of issues with accessing sexual spaces – from (over)protective support workers or parents and the restrictions of

assisted living, to the physical inaccessibility of social spaces, as well as, of course, the widespread discourse that disability and disabled bodies are undesirable. When it comes to physical space, nightclubs and other social spaces are often physically inaccessible to those with mobility impairments, but also come with the ableist ‘we don’t want your sort here’ attitude of staff and other customers, rooted in the discourse that situates disability in private spaces, rather than the public space of the nightclub or restaurant. Ableist expectations around normative sexual behaviour – such as non-verbal flirtation – can make such public social spaces difficult to negotiate if an individual cannot perform such behaviour in the ‘right’ way, if at all (Shakespeare *et al.*, 1996). As Shakespeare *et al* (1996) point out, cultural attitudes to impairment and disability are as much a problem as the issues thrown up by impairments; enacting ‘private’ disability in public spaces leads to public expression of disablist attitudes to add to the issues of ableism.

For people with learning disabilities, their support workers often form the primary friendship and contact group (along with other people with learning disabilities and their support workers), further blurring the lines between public and private when relationships – sexual or otherwise – form within those groups. The intimate affairs of people with learning disabilities are often seen and experienced as public, especially when problematic, or perceived as such (Rogers, 2009).

Pornography, facilitated sex, sexual surrogacy, and paying for sex remains both controversial and complex (Liddiard, 2014; Shakespeare *et al.*, 1996). When it comes to depicting disabled people having sex, there are valid concerns that porn showing disability is made to titillate the non-disabled, and being a fetish object is shameful (Shakespeare *et al.*, 1996), feeding into discourses that exceptionalise disabled people and position them as abnormal. At the same time, being sexualised and shown as a sexual being can be empowering, particularly for those not usually shown as sexual, and disabled people may find seeing disabled porn actors reassuring, in that they affirm disabled bodies⁹⁰ as sexual and sexually desirable (Shakespeare *et al.*, 1996; Sheppard, 2012). While accessing porn is arguably much easier with an internet connection, for those disabled people who receive care can still find their access policed, and struggle to access privacy to engage in masturbation – especially when their carers can perceive them as asexual and child-like.

Facilitated sex – whether facilitated masturbation or sex with a partner – is difficult; care workers may feel unwilling or unable to assist their employers or charges with sexual activity, and may disapprove of the sexual activity engaged in, particularly

⁹⁰ At least, visibly disabled bodies.

when it comes to LGBTQ+ disabled people (Earle, 1999). Including facilitated sex within care troubles the notion of care itself – particularly as care is often positioned in terms of an infantile receiver and adult giver of care. At the same time, the ‘rights’ of disabled people to have facilitated sex and to visit sex workers or sexual surrogates are largely the rights of heterosexual disabled men, while feminine and queer sexuality continues to be controlled (Shildrick, 2009). Shildrick (2009) notes that facilitated sex – and assisting disabled people to pay for sex workers – is arguably illegal, in that Section 31 of the Sexual Offences Act 2003 makes it an abuse of trust to facilitate sex for those classified as ‘mentally handicapped’ (which includes most people with learning disabilities and many with acquired cognitive impairment), while Sections 17 and 21 make it an offence to facilitate sex for under 18s living in care, even though they are over the age of consent. At the same time, sexual surrogacy – whether framed as therapy or as a form of sex work – further medicalises disabled people’s sexuality and sexual activity, reinforcing the medical model in that “dependence on sexual surrogacy may be counterproductive and assumes the disabled person is not able to find their own solution. It may serve to reinforce feelings of inadequacy and difference and suggest that this is the only sexual experience available to disabled people” (Shakespeare *et al.*, 1996, p. 133).

First Sex, Virginity, and Sexual Violence

Unpacking discourses of sex and pain – and of sex and disability and pain – requires not just interrogating discourses of what is considered unusual and abnormal, as in the case of disabled people’s sexual relationships and activities, but also interrogating discourses of the normal – normative discourses of heterosexual romantic relationships and sexual activity. These discourses build expectations for non-disabled and disabled people alike; they are the measures against which non-disabled people hold themselves. Exploring how these discourses shape notions in normative contexts helps to understand how non-normative contexts are designated as such – as well as to understand the normative discourses that shape the lives of disabled and non-disabled people alike.

Within the romantic discourse that shapes the information and knowledge about sex available to young women, sex, particularly first sex and virginity loss, is constructed as a painful experience (Jackson, 2005; Morris, 1991). This discourse “serves as a significant cultural resource in the negotiation of their relationships” (Jackson, 2005, p. 296) for young women, and places young women as responsible for their own pleasure (and therefore lack of pain), but also for control over their male partner’s libido and satisfaction (Jackson, 2005; Lindegaard and Henriksen, 2009). For these young women, there is an expectation that sex will be painful, and that pleasurable

sex is something which must be learnt through the experience of initially painful sex, that if they can endure the pain they will then learn to like sex; that pain will become pleasure if only they would try hard enough.

While this is just one discourse, it leads into another, where discomfort and/or a lack of pleasure in sex is normalised; women are expected to 'fake it' and simulate pleasure and orgasm – in ways much like performers in pornography – in order to support their male partner's masculinity. Faking orgasm is frequently cast as both a necessary and regular part of heterosexual, as a normal part of sex for women in the same way as discomfort is, but is also positioned as a part of a woman's 'duty' to ensure both her own pleasure and that of her male partner, in that she should make her sexual desires clear, while also ensuring that the sexual desires of her partner are met, even if those desires (often phrased as 'needs') do not match up with her own. The emotional care work of faking orgasm can be experienced as pleasurable in itself – in much the same way as other forms of emotional care work can be – and is sometimes positioned as a part of maintaining a long-term relationship due to the discursively normative unequal libidos of heterosexual partners, along with the masculine sexual imperative.

Although sexual violence is not the focus of the research, it is important to touch on – however briefly – that sexual violence can include painful experiences; as previously discussed, unwanted and uncomfortable sex is normalised - and presentations of sexual violence are caught up in those discourses, and sexual violence is itself normalised by those discourses, especially those which present masculine sexuality as aggressive, conquering, and unstoppable. Approximately 30% of women under the age of 60 in England and Wales report experiencing some form of sexual abuse or assault during their adult lives (ONS, 2013; Rape Crisis England & Wales, 2014), with 7.1% of women (and 4.4% of men) in England and Wales reporting an experience of domestic abuse in 2012/2013 (ONS, 2013). Powell (2008) reports that 34% of young women in their teens and early 20s, living in the USA, report experiencing some form of sexual violence. As these figures are broadly similar to those from other Anglo-European countries in the global North it is therefore not unimaginable to extrapolate the following situation as being similar to that in the UK; 6% of young women report forced sex with their boyfriends, while 14% more report attempts (Powell, 2008). Taking these figures into account, it is therefore not difficult to see that while the discursive construction is of first sex as painful, pain may be a common experience for women engaging in penetrative (or other) heterosexual on multiple occasions over the life course.

Sex as a source of pain

In discussing sex and pain, in the context of BDSM and disability it is worth considering the ways in which sex, even heteronormative sex, can be discursively constructed as a source of pain, whether that pain is physical or emotional (or both). This pain can derive from corporeal injury and violence or from symbolic violence, which Bourdieu (1990) situates as a relationship of domination without clear violator or victim. Within heterosexual relationships symbolic violence can be exemplified by “young women who do not refuse unwanted sex because they feel that it would be inappropriate or believe that they are responsible for men’s sexuality which once aroused cannot be stopped” (Powell, 2008, p. 173). While this research is primarily focused on young people in heterosexual relationships (rather than ‘adults’ in established long-term relationships), the discursive constructs, such as the sexual imperative, the gendering of libido and sexuality, and femininity, enacted by the young woman who does not refuse unwanted sex (Barker et al., 2015) are reinforced and internalised (Foucault, 1998) through repeated encounters, and become an expected part of heterosexual sexual activity. The experience – and indeed, expectation of – direct or indirect pressure to engage in unwanted sexual activity is much more common than physical force and verbal threats (Powell, 2008), and while individuals engaging in unwanted

sex⁹¹ may not experience physical pain in terms of a violent wounding, they may nonetheless experience pain as a result of the symbolic violence.

The forms of symbolic violence may differ within localised and racialised contexts, as Lindegaard and Henriksen (2009) observe through their demonstration of respectability discourses within black communities in Cape Town. However, it can also be observed that, for victims of symbolic violence “those who are complicit in their own domination [may] experience a degree of empowerment and those... who resist must secure some kind intersubjective ‘recognition,’ or otherwise risk a paralysing degree of disempowerment” (Mehta and Bondi, 1999, p. 70). For some individuals, adhering to the expected or ‘proper’ behaviour can bring rewards and social approval – and even empowerment – as being perceived by others as a ‘good girl’ (or a ‘respectable person’) may open up opportunities and help smooth social interactions. For those who internalise those discourses of respectability, enacting the roles of ‘girl who needs persuading’ or ‘girl who has sex because it pleases her boyfriend’ can place

⁹¹ Unwanted sex is nonetheless different from forced or non-consensual sex and rape – in that unwanted sex is consented to, albeit unenthusiastically; while it is important to consider the role of consent in delineating sex from rape, it is also important to consider that consent can be given after persuasion and under duress, and is therefore not the sole indicator of that separation – and those who have engaged in unwanted sex may well not have experienced it as a violation of their bodily integrity so much as a chore, something that is neither pleasurable or engaging, but nonetheless must be done.

them in positions of power, having both performed femininity acceptably (and thus maintained their respectability) and maintained their relationships, which themselves can be sources of power and pleasure. On the other hand, resisting respectability discourses (and being a 'bad girl') can work in the opposite fashion, tarnishing future 'good' behaviour; having sex for her own pleasure is unacceptable for properly feminine women, and her peers may, as a result, not recognise her as a 'proper' or 'respectable' person – leading to further painful experiences and a loss of social standing and power.

There are a wide range of discourses available which situate sex as painful, through both symbolic and actual violence. Within romance novels, which are often positioned as 'desirable' or 'ideal' models for heterosexual relationships (especially for younger women, and even though they may not be read as such by those self-same women (Radway, 1984), masculinity is often positioned as harsh or brutal, with heroes demonstrating their masculinity and virility with violence and physical domination. This reflects 19th century sexological discourses and constructions of 'normal' sexuality; women were passive and naturally modest, while men are active pursuers and conquerors⁹² that are still reflected in more current discourses of the sexual imperative and gendered inequalities in libido.

⁹² Particular thanks here are due to Allison Moore, who helped clarify my thinking.

While becoming less common within the genre, it is nonetheless common in romantic novels to see scenes in which “punitive cases [are] dealt with abandon... [with the hero] grabbing the heroine by the arms so hard they leave marks” (Wendell and Tan, 2009). This association between masculinity and both penetration and violence normalises experiences in which sex is painful, particularly for those who are being penetrated. Within romance novels, common tropes also include the hero becoming overcome with love and/or lust for the heroine, and beginning anything from kissing to penetration against her will – at least initially, as frequently the heroine is incapable of resisting (having been too naïve as to understand sexual desire, or indeed, sexual assault), but nonetheless quickly comes to enjoy being violently made love to,⁹³ or too surprised by the hero’s sudden change of mind to do anything but give in to her own desire to let him have his wicked way with her. The ‘modesty’ of the romance novel heroine positions her in such a way that her sexual desire is incapable of existing without the hero’s; he must make the first move before she is able to express desire; this echoes the respectability politics (discussed above) and wider norms of gendered behaviour.

⁹³ This could also be understood as rape, or at the very least non-consensual sex. And lo, did women internalise the ‘she must have secretly wanted it all along’ construction of victim blaming.

Taylor (2011), discussing the *Twilight* novels, draws parallels between romantic heroines and Bataille's position "that eroticism symbolizes the annihilation of self" (Taylor, 2011, p. 32). Within such romance novels "female subjectivity can be entirely dependent on the male Other; a gesture on which the dominant hetero-patriarchal mythologies of romance... So deeply rely on" (Taylor, 2011, p. 33). This annihilation of identity, and of further dependence, is a form of symbolic violence, positioning sex as a symbolically – and also physically – painful experience. These discourses of painful sex are set up in such a way that there are exceptions; sex is painful, but also pleasurable – that the annihilation of the self is necessary for feminine pleasure; modesty is built into 'la petite mort' such that surrendering to a man's lust and power is required before a woman can also surrender to pleasure – even if she should not admit to experiencing the second part in order to maintain her respectability and proper femininity. As a result, painful or violent sex – wanted or not – is normalised, and while romance novel readers may be critical consumers and more than capable of seeing both the tropes and the untruths of romance novel sex, these constructions bleed into wider discourses of uncontrollable male sexuality and the resulting sexual violence, symbolic or otherwise.

Romance novels are normatively associated with women, and women's media consumption; pornography is more normatively associated with men's consumption,

and with 'teaching' young men about heterosexual relationships in the same way that romance novels 'teach' young women. Pornography, while encompassing a huge range of sexual relationships and activities, is generally perceived as "typically [portraying] a relationship between the icons of female victims and male perpetrators (and viewers) with the privilege to 'gaze'" (Gossett and Byrne, 2002). While women friendly and even female gaze pornography has arguably been created (Blake, 2012), the vast majority of *mainstream* pornography can be understood as a demonstration of the male gaze, and primarily produced for consumption by a 'stereotypical' heterosexual man; young, able, and white. The parallels between romance novels (to be consumed by heterosexual women) and pornography (to be consumed by heterosexual men) can be glaringly obvious – just as the romance novel protagonist is modestly confused by the hero's attentions, and sex is the result of her being overcome by his masculinity, the female porn actor is overcome by her partner's obvious hyper-masculinity and acquiesces to sex in which the final conclusion is always his pleasure.

There is no agreement on the link between pornography and rape, but more agreement on a link between violent porn and misogynistic attitude amongst viewers (Gossett and Byrne, 2002); MacKinnon asserts that porn performs violence on women otherwise seen in real life (1993). While both of these can be disputed (and frequently

are), the imagery in pornography is often readable as violent, with certain acts conceivably uncomfortable if not actually painful for performers. Osterweil, in examining Andy Warhol's short film *Blow Job*, observes that "spasms associated with sexual pleasure bear very great resemblance to expressions of boredom, irritation, and pain" (Osterweil, 2004, p. 435); within mainstream pornography it is often difficult to determine if performers are enjoying themselves, in pain, or simply fulfilling a chore in much the same way that 'real life' women may well engage in unwanted sex. This contestatory positioning of pain/pleasure in mainstream pornography echoes the discourses of female sexuality as passive, while properly masculine sexuality is aggressive, uncontrollable, and irresistible. While the discomfort of female performers is not the selling point, such pornography arguably does discursively construct sex as normally painful for women (or for the penetrated party). This ties to wider discourses of penetration as a violent act and to the ways in which penetrating is coded as masculine, while being penetrated – and therefore suffering pain – is coded as feminine.

In non-mainstream pornography, or in pornography that shows specific uncomfortable/painful acts, such as gang-bangs or spanking,⁹⁴ the pain experienced

⁹⁴ I include BDSM pornography within this, although I would contest that BDSM porn differs in that the pain is both *intentional* and consensual.

by those shown may in fact be a selling point. Gossett and Byrne, in their study of on-line rape porn state that teaser images of the victims⁹⁵ typically showed “the victim’s face [with] an open mouth, as if screaming or expressing pain” (Gossett and Byrne, 2002, p. 700). In such videos and images, pain is a primary selling point; “no descriptive words are used to portray rape as romantic seduction, such as discussions of passion or overwhelming love for the victim, and there are no sites that have descriptions in the text of women enjoying the rape of wanting it” (Gossett and Byrne, 2002, p. 703). In contrast, BDSM pornography, such as that produced by kink.com, often includes performers discussing their consent to, or enjoyment of the scene, even in video trailers – while producers in this situation also use pain and violence as selling points, the consent of the performers is *also* a selling point, an explicit destruction of the fantasy play that is necessary in order to position the pornography (and, by extension, the people involved in making the film) as both responsible and acceptable. It is worth noting that these scenes of consent or post-scene discussions of enjoyment are not seen in mainstream pornography, even those including scenes where performers look to be in pain.

⁹⁵ While Gossett and Byrne (2002) state that some sites did indicate that the scenes were acted, the rest either did not say anything, or advertised ‘real rape’, and thus I have kept their terminology.

Painful sex

To turn to painful sex outside of sexual or symbolic violence, pain during or after sex is often positioned as a negative experience requiring expert, medical, attention; while, for women and gay men, penetrative sex is 'supposed to be' painful at first, sex and pain are positioned as not overlapping, even when sex is not pleasurable or is unwanted. For women, painful sex is often positioned in such a way as to be the female equivalent of erectile dysfunction, and is more broadly positioned under the umbrella of sexual dysfunction, although there is no real consensus on what sexual dysfunction *is* in medical terms (Verschuren *et al.*, 2010). Nonetheless 'normal' sexual function is tied to quality of life and psychological well-being, with the medicalization of treatment⁹⁶ becoming increasingly the norm.

When disability and chronic illness is included, the medicalization of disability⁹⁷ leads to the assumption that painful sex, for disabled people, must be a medical problem rather than the result of a lack of knowledge,⁹⁸ or a sought experience. At the same

⁹⁶ See p.96 for medicine and pain.

⁹⁷ See p.40 for the medical model of disability; see p.96 for medicine and pain.

⁹⁸ Despite concerns raised around the lack of sex and relationships education given to young disabled people (Barron, 1997; Rogers, 2009; Shakespeare *et al.*, 1996).

time the asexualisation and infantilisation of disabled people leads to assumption that they will be not be having sex in the first place. However it is to be noted that while older discourses create a certain squeamishness about disabled people's sex in the medical field, those in the arenas of sexual health and sexual self-help (and to a lesser degree, sexology) can be equally as squeamish, and often ignore disability and non-normative sex (Owens and de Than, 2014), and there is often feeling that disability is a step too far when talking about sex (it is also possible that researchers and writers themselves don't feel comfortable crossing into from one area to the other, due to a lack of existing discussion and writing). This squeamishness with sex can extend to those working with disabled people, and in the field of disability studies; discussions of sexuality and sexual activity are frequently confined to the twin spheres of 'sex education' and 'managing sexuality.'

Within medical knowledge (and as a part of the project of medicalising pain⁹⁹), as Ruehleman *et al* (2008) observe, there are a limited number of studies looking into sex and pain conditions; "those few[studies] have revealed: (a) that pain may precipitate sexual difficulties, and (b) that sexual activity may aggravate pain, sometimes leading to a reduction or complete cessation of sexual behaviour, decreased satisfaction, or impaired performance" (Ruehlman *et al.*, 2008, p. 124). Figures ranging from 56% to

⁹⁹ See pp.96, 118.

71% of pain clinic patients across four separate studies revealed pain having a negative impact on patients' sex lives (and by extension, the sex lives of their monogamous partners¹⁰⁰) (Ruehlman *et al.*, 2008); Ruehleman *et al.*'s (2008) own figures were significantly lower, but included people with chronic pain not seeking medical help at the time of the survey.

Significantly, Ruehleman *et al.* state that "greater interference with sexual activity is associated with higher levels of tangible support and impatience.... The person with pain who receives greater tangible support may be communicating messages of weakness and frailty to the social network, resulting in both greater support and a feeling of impatience in the supporter. These same messages may be barriers to sexual activity" (Ruehlman *et al.*, 2008, pp. 132–135). However, while not disagreeing with these findings themselves, I would disagree with the interpretation, positing instead that support leads to a greater cementing of the perception of the person in pain as disabled, which effectively positions in such a way as that asexualisation and

¹⁰⁰ In all of these studies those experiencing pain were assumed to be heterosexual and in monogamous relationships; no mention was made of non-heterosexual individuals, those in polyamorous relationships, non cis-gendered individuals, or any combination thereof.

infantilisation discourses come to the fore,¹⁰¹ positioning them as no longer sexual beings.

Sexual Pain: BDSM

When it comes to sex and pain, to pain that we embrace and pain that incapacitates us, it is of course important to consider painful experiences that are sought out and consented to as part of erotic activities. Pain is not necessarily a central feature of all BDSM¹⁰² – indeed there are plenty of activities that involve no pain at all (Langdridge, 2007a) – but nonetheless erotic pain remains firmly associated with BDSM.

There has been a movement away from the perspective that BDSM and being ‘kinky’ is pathological, and while this discourse remains largely dominant, recent changes to the DSM – IV state that engagement with BDSM is not in itself pathological unless it causes distress to oneself (American Psychiatric Association, 2000). Much of the work

¹⁰¹ See p.132.

¹⁰² BDSM stands for bondage and discipline, dominance and submission, sadism and masochism (Bauer, 2014; Langdridge and Barker, 2007; Taylor and Ussher, 2001).

moving away from pathological perspectives is spread across various disciplines, and it should be noted that BDSM communities have a “complex and contradictory nature... in which some elements seek to merely extend ‘everyday’ sexuality whilst others seek to provide an alternative that challenges and confronts” (Langdridge and Butt, 2004, p. 45), presenting BDSM practices as forms of legitimised violence as well as acts of love and playful eroticism. These presentations can be seen as paralleled to the responsible homosexual versus dangerous queer discourse (Smith, 1992), with the good kinkster versus the bad edge-player and bad queer sharing a complex and convoluted bed. In this good/bad dichotomy, the good kinkster is one whose practices could be described as ‘extending’ sexuality; their practices are erotic, and performed within consensual committed relationships, carrying no risk of long-term damage; the bad edge-player is one whose kinks involve blood, sharp edges, breath play, and non-erotic or uncommitted relationships, whose practices run the risk of scarring, or otherwise seriously injuring – or even killing – their submissive or slave.

Langdridge and Butt (2004) posit that acceptance of BDSM in some media versus non-acceptance in governmental policy is possibly due to the emphasis on the sexual in many media portrayals, rather than love and responsibility; these media portrayals can also be read as a fetishization of BDSM itself, a voyeuristic and commercialising approach that does little to benefit BDSM practitioners or those seeking knowledge

over titillation. Beckman observes that “decontextualized elements of SM and of fetish culture have become integrated for profit. However, while this development on the one hand opens up possibilities of engagement and transgression of the realm of normatively imposed ideas about what constitutes normal sexuality, it is crucial to reflect on capitalism's tendency to facilitate the commodification of apparently 'kinky' sex” (Beckmann, 2014, p. 109); commodified elements of BDSM tend to be reserved for conventionally-attractive, young, hetero- and homo-normative couples, on the edges of the good kinkster discourse, and instead of including BDSM in normative sexuality, further reinforces the binary between normative-good and abnormal-bad sexualities and sexual practices.

Within academia BDSM is also positioned as about sex and the erotic, “despite recognition that SM is not always considered sex by participants ... [with] some SM participants [rejecting] a sexual context for their S&M participation” (Newmahr, 2011, p. 66). This is not tidy delineation however; there is a great deal of variation across BDSM communities as to the level in which BDSM involves sex or sexuality, including a discussion of whether ‘kinky’ is in itself a sexual identity rather than a series of bodily practices. The difference between the two is whether or not a person who engages with BDSM is doing so as a form of bodily practice – erotic or not – but does not identify those practices as a key aspect of their selves, and is instead engaging with

BDSM in the same way as they engage with hobbies – or whether BDSM is a key aspect of their sexual selves, defining who they are attracted to, have sex with, and how they go about having sex – and thus it impacts on their wider social identities in the same way as being gay or asexual, and as such can be considered a minority identity in receipt of stigma.

Much of the work that seeks to depathologise BDSM, or sits outside of the pathological standpoint, situates BDSM as “about dominance and submission and not necessarily about pain... While it is true that pain is important to some sadomasochists, and it is certainly possible that pain can be eroticised, definitions of sadomasochism that focus exclusively on pain miss the essence of SM, the ritualization of dominance and submission” (Weinberg, 2006, p. 33). While Weinberg (2006) uses the term SM,¹⁰³ he tends to conflate SM and BDSM, ignoring that BDSM is an umbrella term for a much wider range of activities, and *includes* SM. It is perhaps this conflation that leads Weinberg (2006) to assume that all BDSM is erotic, whereas there are plenty of activities, particularly forms of dominance, submission, bondage, and discipline that are not engaged in for the purpose of erotic excitement or

¹⁰³ SM here stands for sadism and masochism, whereas BDSM stands for bondage and discipline, dominance and submission, sadism and masochism; the latter encompasses a wider range of practices and preferred terminology, although there is also a great deal of overlap.

pleasure.

For Taylor and Ussher erotic and play pain can be more about “subjective experience of pain rather than the infliction of bodily damage” (Taylor and Ussher, 2001, p. 299) – it is about the psychological nature of pain, and its relationship to power, rather than purely about physical sensation. However it is worth noting perhaps, that in moving away from pathologising BDSM, the focus on power relations has led to pain within BDSM being quietly shuffled off to one side – in Kleinplatz and Moser’s edited volume *Sadomasochism: Powerful Pleasures* (2006), pain is not listed in the index at all, while in Taylor and Ussher’s (2001) discourse analysis of SM, pain is mentioned across discursive themes, but it is not in itself a theme they identify when participants talk about their SM practices. In *Safe, Sane and Consensual* (Langdridge and Barker, 2007), pain is discussed in only one chapter, as “the unspeakable” (Langdridge, 2007a).

To return to an earlier point,¹⁰⁴ this parallels the ‘good gay’ and ‘bad queer’ (Smith, 1992); pain, like other challenging and confronting practices in BDSM, is a part of the unspeakable, dangerous side of BDSM, one that is difficult to portray as ‘normal’ particularly once it moves away from lighter pain play that runs little to no risk of

¹⁰⁴ See p.159.

bodily harm (and might instead be termed *sensation play*) towards the heavier, and therefore riskier, practices. The good kinkster plays with sensation, while the bad edge player uses pain and violence. While this essentialises pain in BDSM, the unspeakable part of pain means that aspects of BDSM practices that engage with pain, and confront and challenge constructs of pain, are largely silenced – and certainly not discussed with outsiders. This practice of silencing means that BDSM pain is divorced from other pain through discourses within the subculture. Because pain is still perceived to be a negative experience (due to both BDSM-specific and wider discourses), and it is pain and its association with violence that allows for BDSM to be pathologised. Considering painful play – and play that causes pain – may be too close to pathologisation for comfort, particularly when attempting to present a ‘good kinkster’ representation of BDSM practices.

The discursive construction of BDSM as play (albeit play that needs to be worked at as serious leisure (Weiss, 2011)) can be read as further removing pain from a position of importance in practices, as there is a jarring disconnect of wider constructions whereby pain is situated against play and enjoyment. Play “references recreation and leisure, and evokes a romantic sense of innocence and freedom from encumbrances” (Newmahr, 2011, p. 8); this can be tied to a sense of fantasy that is often observed to be a mainstay of BDSM scenes (Langdridge and Barker, 2007; Newmahr, 2011; Weiss,

2011), while pain references the unavoidability of everyday life, and the violence of unequal power relations that exist outside of carefully staged unequal power relations in BDSM.

The scripting of BDSM play relies on social context and social power relations that give specific contextual meanings to play scenes (Weinberg, 2006), so while these scenes may be about the rejection of dominant norms (Plante, 2006; Weiss, 2011), they are also socially controlled and formed by them. Scenes use dominant norms (such as how dominance or violence is performed, with what instruments, or in what setting) as well as playing with them, testing their limits, or challenging their performativity – for example, medical play challenges the norms of the medical setting (one that is firmly desexualised) but also relies on the demarcation of certain instruments, clothes, or language as ‘medical’ in order to indicate what norms are being challenges, as well as appeal to the participants’ desires and pleasures.

Divisions within BDSM occur along multiple lines; tensions exist along these lines and within communities, and normative constructions cannot be considered as fixed.

Broadly, divisions occur along the lines of geographical location, of sexuality, of preferences for particular activities, and between ‘old guard’ and ‘new guard.’ Weiss defines the old guard as members of the primarily homosexual leather scene between

the 1950s and 1970s, while from the 1980s onwards, the new guard – or new school – are pansexual, and less concentrated in urban centres (Weiss, 2011). Rubin (1998) separates the new and old guards along degrees of in/formality, adherence to particular forms of etiquette, and the learning of skills rather than training; like Weiss, Rubin locates the old guard in the homosexual leather scene. Baldwin (1991) explains that the old guard's focus on ritual and formal rules originates in the large numbers of scene members in the 1950s onwards who were also military ex-servicemen, due to conscription and national service. The new guard, being less formal or rule-focused (and, justifiably, less concerned about the risks of a wider and more open membership following the legalisation of homosexuality, although BDSM involvement still carries a stigma (Kleinplatz and Moser, 2006; Langdridge and Barker, 2007; Taylor and Ussher, 2001; Weiss, 2011)), is less easily identifiable than the old guard; as Bauer explains, "the social organisation of the Old Guard has mostly been replaced by a community that is open to anyone interested in joining, that educates its members through handbooks [rather than a system of training and 'apprenticeships'], workshops and so on and that forms broad national and transnational alliances to fight for social acceptance and public recognition" (Bauer, 2014, p. 20).

Within BDSM communities and activities, there are a series of normative constructions around who does BDSM, in terms of who can or should play in shared or

(semi)public spaces. Some of these constructions may be pornonormative (Newmahr, 2011) in terms of what aspects of play are marked as 'erotic' or 'sexy' (slim, large-breasted women in PVC catsuits, lingerie, waxed or shaven genitalia, and so on and so forth – the imagery often associated with pornographic depictions of BDSM).

Pornonormative constructions of BDSM are largely focused on visual aspects, on achieving a certain visual aesthetic in terms of how bodies look, having the 'right' clothes and equipment, but are also about what acts constitute BDSM play.

Pornonormative play is intended as erotic – there is no space for BDSM that is not about eroticism – fitting into normative constructions of the masculine-dominant and the feminine-submissive, with play that is intended to titillate an audience and the players, rather than explore or challenge the power in a relationship. Other normative constructions may depend instead on the domination of clubs and public play spaces by white, non-disabled, middle-class people (Bauer, 2014, 2007; Langdridge and Barker, 2007; Santilla *et al.*, 2002); these aspects often tie into pornonormative constructions of BDSM – particularly when it comes to acquiring particular equipment, or being able to play publicly without one's presence or actions being called into question.

Within the various scenes and communities, the opposition of pain and violence against eroticism and play makes a "conscious and deliberate relationship between

the erotic and the violent... ethically unacceptable” (Newmahr, 2011, p. 126), even within sadomasochism. As Newmahr observes, this leads to a difficult and problematic relationship whereby pain is often reconceptualised as not ‘really’ violence or pain, but instead as a *performance* of violence, a simulation, complete with symbolic trappings that situate violence and pain within non-sexual contexts, some requiring a degree of ‘make-believe’ role-play. This is perhaps in part of the problem of pain, and how BDSM problematizes the relationship between pain and violence; when pain is considered to be the result of violence, and that as violence is positioned as negative, as uncivilised, then pain must also be negative and uncivilised - a pairing that practitioners must retreat from in order to avoid BDSM practices as being perceived of as negative and uncivilised (any more than they already are). This conscious stepping away from pain and violence as a central part of many, if not all, BDSM practices places practitioners in a complex position, where they must legitimise their desire to experience and/or cause pain, while also distancing themselves from the self-same narratives and norms which describe the imbalances of power that characterise the social contexts they challenge and play with; they can only be *playing* if they have first proclaimed that this is *not us* – once they have disavowed their own place within social power relations. This disavowal-before-play is similar to the relationship BDSM has with traditional/mainstream models of masculinity; before playing with masculinity, practitioners first recognise the problems of the performance – and thus their masculinity during play is in the way of a parody, and a disavowal, just as the

pain in play is also a disavowal of the violence and unequal power relations in traditional/mainstream heterosexuality.

Newmahr, in her ethnographic study of a BDSM community in San Francisco (2011), identified multiple reframings and discursive twists through which participants legitimise experiencing and causing pain. The first of these, the *transformed pain* discourse, “relies on a conceptualisation of pain as an objective stimulus which may or may not result in the *feelings* of hurt... This ‘processing’ of pain sensations as pleasurable, within seconds or less, fuels a discourse in which pain can be *real* but not *bad*...[Reconciling] masochism with rational thought; if pain does not ‘really hurt,’ it is depathologised, and therefore it’s enjoyment is unproblematic” (Newmahr, 2011, p. 135 italics original). Transformed pain is not *really* pain, and it is the performative nature of BDSM which allows it to be thus, in the same way that the dominant participant is only dominant with the consent of the submissive, the bound participant is easily freed, and the age-player’s nappy is not needed once the scene ends. This depathologising relies on the recognition of performance and play, but also on the explicit denial of the construction of pain in the scene (or of dominance, of bodily restriction, or of incontinence). In order for pain to be transformed, the person experiencing pain must first recognise themselves as not *normally* in pain and that pain is *normally* bad. It also relies on a conception of pain akin to the Specificity

Theory,¹⁰⁵ where pain is straightforward somatic sensation – and it is only the conscious interpretation of that sensation which marks it as pain. This reframing is also commonly found in the ‘good kinkster’ reframing of BDSM, as one which uses sensation for erotic gratification, but denies that the sensation may be produced through violence.

Newmahr’s (2011) second reframing of pain, termed *sacrificial pain*, was found particularly in discipline and punishment scenes, and situates pain as a sacrifice on the part of the bottom for the good of and desires of the top; it is the top, the dominant, who is the sadist, or who needs to express a part of themselves through activities which cause pain for others; the submissive endures but does not enjoy, with their endurance acting as a form of service to their dominant. Newmahr observed this as a particularly gendered discourse, frequently expressed by submissive women in D/s relationships; it is less easy to align this reframing with the ‘good kinkster’ – particularly when the good kinkster is one who challenges normative constructions of gender and power imbalances – but it is echoed in discourse which position the dominant practitioner as having a particular knowledge and/or skill-set that enables them to ‘know’ what the submissive needs, and if the submissive endures to a particular point, they will be themselves transformed, or able to access the place in

¹⁰⁵ See p.97.

which pain is no longer anything other than sensation.

The third reframing discourse Newmahr identified is equally as gendered, with *investment pain* as a hyper masculine discourse which promises future rewards. This is most frequently paralleled within discourses of pain and reward in sports. Investment pain “is understood not merely as an unfortunate by-product, but as a means to a particular end. While hurting is not the goal, in and of itself, it is rewarding for both what it evidences and what it produces” (Newmahr, 2011, p. 138). This pain is not experienced or endured for the sake of others, and is not sought out by either bottom or top, but is instead a mark of one’s ability to achieve a particular state. This is echoed in the knowing dominant/naive submissive construction discussed above, particularly in terms of pain being transformative and itself transformed, but the process of enduring is in itself important – the process of being able to take it better, to last longer, to be better.

Newmahr identified only one discourse, very much in the minority, whereby pain and the relationship with it is framed in positive terms; in what she has termed “autotelic pain” (Newmahr, 2011), pain is liked as *pain*, for pain’s sake. For those who situated pain as autotelic, “the pain hurts, but hurt also feels good. Participants who frame pain in this way have an extraordinarily difficult time articulating their experience of

pain. They generally distinguish between kinds of pain that they do like and kinds of pain that they do not like; the particular kind of pain, rather than the context, determines whether the response is favourable ... Among these participants, *eroticism* is often denied or recast. Most of the people who say that they like to hurt or be hurt also say that SM is not sexual for them. And those who do use the word 'hurt' draw the line between 'hurt' and 'harm' with the distinction being largely temporal; harm is lasting" (Newmahr, 2011, pp. 139–140). This discourse relies on, and reinforces, the positioning of pain and violence as the antithesis of pleasure and eroticism; rather than denying the painful aspect of BDSM practices, practitioners instead deny the erotic – and continue a framing of BDSM whereby violence and eroticism cannot exist together. This discourse of autotelic pain is perhaps closest to what we would recognise as 'true' masochism, the enjoyment of pain and denigration for its own sake, in that it conceives of pain as *painful*. However, as it has nonetheless been shown that state of mind and intent alters the experience of painful events (Kleinplatz and Moser, 2007), it is just as conceivable that people who reframe BDSM pain as not painful are not experiencing the pain we understand as the result of injury or violence.

Despite Newmahr's (2011) work, pain as an embodied experience, as a bodily experience for BDSM practitioners, remains largely side-lined by considerations of power and of the legal standing of BDSM. While I posit that this is due to a degree of

discomfort with problematic relationship between pain, violence and play, it is also undoubtedly due to the relatively small size of the field when it comes to academic enquiry into BDSM.

Bob Flanagan

No exploration of BDSM and chronic pain would be complete without reference to the artistic work of Bob Flanagan, and his partner and Mistress, Sheree Rose. A re-reading of Flanagan's (and Rose's) art is not particularly necessary at this point – nor is an in-depth exploration of previous work about Flanagan and his work – as this is only tangentially connected to the thesis.

Kolářová describes an exhibition of Flanagan and Rose's thus;

"As an introduction to Flanagan's art of pain and pleasure, we might tour one of Bob Flanagan and Sheree Rose's best-known and biggest museum installations, *Visiting Hours*, which opened in Santa Monica Museum of Art in 1992. The exhibition starts in a "waiting room," and though references are made to a hospital setting, soon enough it is clear that Flanagan and Rose

initiate the visitor into a very different version of a hospital. Sitting down on the waiting room couches, the visitor finds the usual magazines splayed out on the end table. Children's magazines on first sight, on a second, however, they give out the clue to the difference of the cure this hospital offers. It is not cartoons but S/M visuals that one finds between the covers. Posters of S/M instruments that hang on the walls next to the medical images that adorn the room. Cacti in suggestive phallic shapes with no less suggestive thorns stand in one of the corners." (Kolářová, 2010, p. 45).

Multiple readings of Flanagan's art – made with or without Rose – are possible. As McRuer observes, "Flanagan's images sometimes suggest little more than 'Bob Flanagan's sick.' In a moment of danger and non-compliance, however, 'some future person' or collectivity might detect in that sick message the seemingly incomprehensible way to survive, and survive well, at the margins of time, space, and representation (they might, in fact, detect that surviving well can paradoxically mean surviving sick" (McRuer, 2006, pp. 182–183). McRuer (2006) reads Flanagan's arts as embracing queer/crip possibilities, as well as rejection of a compulsory able future, a performance of a complex lived experience rather than one of 'overcoming' disability.

Kolářová, viewing Flanagan's art with the same eye towards queer/crip possibility, writes that "it is possible to perceive Flanagan and Rose's erotic and S/M

performances as (crip) investments in reinventing the body outside the medical spectacle and gaze." (Kolářová, 2010, pp. 45–46). It is Flanagan and Rose's crip speaking back to the medical gaze that Reynolds reads most strongly, drawing attention to the contrast between chosen-consensual kink and unchosen-consensual medical care in their performances of *Visiting Hours* (Reynolds, 2007). Reynolds' reading is perhaps most pertinent in relation to this thesis,¹⁰⁶ observing that "through various tortures, Flanagan was able to gain physical and psychological control over a body that was frequently out of control. Flanagan's self-imposed restrictions and degradations served as an entertaining way to keep his reckless, unpredictable body in line. These restrictions, Flanagan argued, poked fun at the seeming arbitrariness and cruelty of his illness" (Reynolds, 2007, p. 43).

Key Ideas: A Summary

To recapitulate the conception discussion of the last three chapters, whilst this study draws from a range of sources, it uses a Crip approach as the main, unifying, theoretical framework, rooting the research in disability. Crip enables links to develop between understandings of disability and other bodymind experiences, including pain

¹⁰⁶ See chapter on control, beginning on p.264.

and sex; crip ideas of time serve to unpick notions of chronic and acute pain. Crip also links to concepts of abjection and control, and the role that both of these play in how disability is experienced.

The research starts out from a crip standpoint, a critical approach centralising the role of compulsory able-bodymindedness, or ableism, in neoliberal society (Goodley, 2014; Kafer, 2013; Kumari Campbell, 2009; McRuer, 2006). Crip theory takes its cue from Queer Theory, critiquing the idea of a socially-constructed 'normal' through the concept of disability, and develops how modern-day society enforces not just what constitutes disability, but places the non-disabled bodymind as the normal – and normative – experience, as well as the ideal. McRuer called this compulsory able-bodiedness (2006) – developing the idea of compulsory heterosexuality (Rich, 1994). I have, influenced by Price (2015), chosen to refer to bodyminds and able-bodymindedness – rather than able-bodied and able-mindedness.¹⁰⁷

Taking a critical, crip approach focuses primarily on disability as an experiential and self-expressed identity – in that disability is imposed and inscribed upon certain bodyminds by social structures and the readings of that bodymind by others, and then

¹⁰⁷ See p.20 on language choices.

disability is claimed by that bodymind as a part of their self; *I am disabled*. This approach provides a central starting point to tie together several other theories and readings, while also taking a political stance challenging neoliberalism and ableism more broadly. A critically crip approach, “[sees] ‘disability’ as a potential site for collective reimaginings” (Kafer, 2013, p. 9), centering the narratives of disabled people, and unlike the social model (which it, and the research, owes much to) it has room to consider the experience of pain as a part of disability.

A crip reading of disabled people’s sexuality and erotic experiences posits that, as normative understandings of sex and sexuality involve able-bodyminded individuals (Dune and Shuttleworth, 2009; McRuer, 2006), disabled people’s sexual activity, whether solo, with other disabled people, or with able-bodyminded people, can be understood as non-normative, no matter how normative or ‘vanilla’ their sexual practices may be (Kumari Campbell, 2009). This non-normativity is of course imposed upon their sexual activity, and those self-same disabled people may not view their sexual activity as particularly non-normative. This is not a particularly revolutionary understanding of disabled people’s sexual activities in and of itself, but it does position it in such a way as to strengthen parallels between disabled people’s sexual activities and other non-normative sexualities, from queer sex to BDSM; it opens up spaces where communities can learn from each other. Painful sex can be positioned as

both non-normative and normative, as acceptable and unacceptable, and this fluidity means that crip readings, which encourage fluid and changeable understandings, lend another dimension to this understanding.

There is little work that considers disability and BDSM, although Aguilera (2000), Solvang (2007), Kumari Campbell (2009), Kafer (2012) and Harmon (Harmon, 2012) have all explored the concepts and experiences of disability, devotees (people with a fetish for disabled bodies), and wanabees (transabled people¹⁰⁸). Outside of the academy, there is a small but significant wealth of knowledge, some of which was collected in a small volume, *Playing With Disability* (Stassiopoulos, 2007). This volume, while interesting, focused primarily on the practical aspects of disability and BDSM from a personal/individual aspect, and was not consistently political in its approach to disability as identity, instead focusing on individual stories that did not consider how disability is impacted by wider sociocultural factors.

¹⁰⁸ Transabled people, or wanabees, are people who are currently non-disabled, but identify as having a specific disability (such as an amputation or hearing impairment) and live as though they were disabled; some wish to have surgery to alter their bodies. I have yet to find a transabled person who desires to become cognitively or mentally disabled, or acquire a learning disability.

Pain, chronic or otherwise, is contentious within disability rights and academic work,¹⁰⁹ with some, such as Oliver (2013) arguing that because pain is a universal sensation (because everyone, able and disabled alike, experiences pain at some point in their lives, even if that sensation is experienced differently) pain and illness is not an impairment. Others, with whom I am more sympathetic, identify chronic pain and chronic illness as disabilities, albeit those that lack the fixity of more familiar, unvarying disabilities (Wendell, 1996). Within academia, explorations of pain have rarely considered chronic pain, except from a medical viewpoint (which often takes the viewpoint of disability as individual tragedy requiring rehabilitation) (Barnes *et al.*, 2002; Best, 2007; Seymour, 1998); they focus instead on the experience of acute pain, frequently for non-disabled individuals. Within studies of disability and ableism, pain is, again, rarely considered; the few exceptions take either an overwhelmingly negative view of the experience of pain (Siebers, 2006), or include it only in passing (Wendell, 1996).

Chronic pain is broadly understood as being long-lasting; in medical understanding pain needs to have been experienced for several months or more to qualify as chronic. The exact point at which acute pain – or immediate pain – becomes chronic is hard to define outside of medicine (and frequently even within), perhaps due to the lack of

¹⁰⁹ There is a great deal of overlap between these two, but they are not always the same thing.

attention given to the experience from the viewpoint of patients. In exploring pain, I considered it important to at least acknowledge the way in which pain is conceived of in relation to sex (outside of BDSM-specific contexts), with particular reference to pain as the result of symbolic violence (Powell, 2008), and pain in virginity tropes (Jackson, 2005). This is joined with an exploration of how pain is conceived of in wider culture, with particular reference to religious ideas of pain and suffering, and medico-legal perceptions of pain.

Pain is under-researched in explorations of BDSM, particularly those which seek to de-pathologise or oppose a pathological standpoint; these instead are more involved in understanding power. While power is undoubtedly a – if not *the* – central force in BDSM relationships, this has led to an under-theorising of the experience of pain. Like much research into BDSM, those works that do consider pain (notably Newmahr (2011) and Langdridge (2007a)), do so from a non-disabled, and arguably ableist, viewpoint that situates pain as an acute experience.

The third key concept is a combination of the concept of abjection, and that of control. For abjection, while it is rooted in the work of Kristeva (1997), I primarily used the work of Imogen Tyler, who situates abjection in neoliberal times (therefore paralleling nicely with the work of McRuer (2006), and Goodley (2014), both of whom

write on dis/ability in neoliberalism), and focuses on the experience of being abject (Tyler, 2013). This is useful when considering the disabled and chronically ill experience, as an abject other, but also in considering pain, which may be experienced, or result in, self-abjection. In considering abjection within disability, the role of control is important – both the need to control the disabled body (Shildrick, 2009), but for the need in neoliberal society for self-control (McRuer, 2006), as a way of avoiding becoming disabled.

This positioning of disability as a failure of self-control within a risk society (Beck, 1992; McRuer, 2006) is particularly important when considering the abjection of people with chronic illness (as well as other acquired impairments), and the internalisation of this abjection, and how it ties into internalised ableism. Within this positioning, acquired impairments and chronic illnesses are cast as a result of an individual failing to adequately prepare against and mitigate risk – whether from not taking the “right” steps to ensure their physical health, or by engaging in dangerous activities – for example, ME/CFS is cast as a response to stress (particularly work-based stress, in women). The individual is then also responsible for ensuring they do all they can to ‘cure’ or ‘manage’ their disability – by eating the ‘right’ foodstuffs,¹¹⁰

¹¹⁰ Recently Women’s Hour on BBC Radio 4 ran an interview with a young food blogger discussing how ‘eating clean’ had a positive effect on her Postural Tachycardia Syndrome (“Woman’s Hour,” 2015).

doing the 'right' exercise regime, taking the 'right' medications, or using prosthetics and implants. This individualised, medicalised approach to disability disavows collective identity, and enables not only able-bodied others to perform abjection, to judge the disabled person (particularly if they are considered to not be doing disability in the expected way – such as being 'too young to need a walking stick'), but forces the disabled person to judge themselves, to continuously reflect on what they should have done better, to perform abjection against themselves – and against other disabled people, positioning them as 'scroungers' and 'lazy,' while disavowing their own experience, or the possibility of collective identification.

Thinking around abjection and control may also be useful for thinking about the experience of pain itself (rather than chronic pain as impairment leading to disablement), and also when it comes to working through control in receiving pain in BDSM activities. When it comes to BDSM and pain, the key work of Staci Newmahr in categorising how participants rationalise their use of pain is a useful starting point (Newmahr, 2011), as is Langdridge's analysis of erotic pain (2007a), referring to the work of Scarry (1985) in which pain is cast as beyond language, and without a referent; in both, pain is essentialised as both short-term and the product of violence.

Chapter Four: Methodology

This chapter – as the title implies – is an account of the methodology used in the research. Beginning with the research structure and differences between the initial plan and what actually occurred, it will move into the theoretical background of the methodology, and how theory and my own positioning as a disabled research impacted considerations of structure, accessibility, and consent. Participant profiles are included at the end of the chapter.

Research Structure

I intended to interview somewhere in the range of eight participants, no fewer than five, but I imagined more than ten or twelve might have been difficult,¹¹¹ especially given the sensitive topic of the research – and the likelihood of there being only a relatively small population who fitted the description of ‘living with chronic pain and also into pain as a part of BDSM play.’¹¹² A small sample was also chosen to give

¹¹¹ The Call for Participants (see Appendix 2, p.346) initially asked for 8 – 10 participants.

¹¹² See p.15 for (separate) population figures of people living with chronic pain and people into BDSM.

opportunity to delve into details narratives without becoming wholly overwhelmed with the volume of raw data. In the end, the interviews alone generated more data than could reasonably be used in the thesis.

The intent was for the interviews to take place over a period of ten to thirteen months, with an initial pilot interview taking place as soon as possible after the prospective participants getting in touch with me. The initial plan was that each participant would be interviewed three times within the timespan, and asked to keep a journal exploring their encounters with pain within the context of their daily experience of impairment, and their erotic activities.¹¹³ The interview timeline (see Figure 1, below, for diagram) was to be as follows:

- Interview 1: life history, open questions as per call for participants
- Blog/diary/journal: bimonthly, reflection and events, in format chosen by participants (see Appendix for template)
- Interview 2: Specific questions following from Interview 1 and diary, to take place approximately six months after Interview 1
- Blog/diary/journal: optional, with participants encouraged to reflect on first six months of study

¹¹³ See Appendix 5, p.380 for diary suggestions given to participants

- Participants given transcripts and notes from Interviews 1 and 2, diaries, within six weeks of Interview 2.
- Interview 3: reflection on previous interviews and diary entries, to take place within four to six months of interview 2.
- Participants given transcript of Interview 3 and corresponding notes within 4 weeks
- Participants will then have 4 weeks to ask for amendments or withdrawals, after which the transcripts will be finalised.

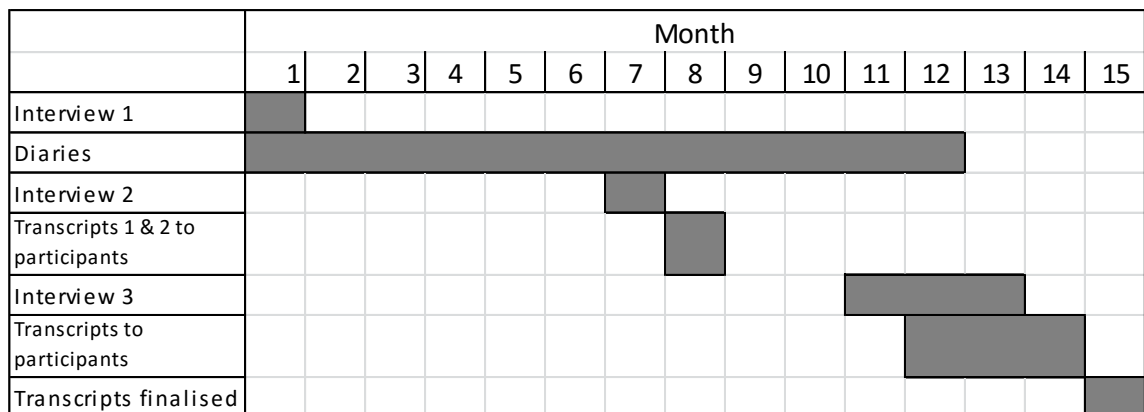


Figure 1: planned timeline for interviews

In the end, I interviewed eight participants, and three dropped out after the first interview, with the remaining five completing all stages¹¹⁴. The interview process took a little longer than initially planned - mostly because transcribing the interviews took

¹¹⁴ See p.226 for participant profiles.

longer than I hoped, and non-academic commitments interfered on occasion. This meant that the final few months felt a little rushed, but overall, the process was unremarkably straightforward. A second timeline, describing the actual time the research took, is shown below:

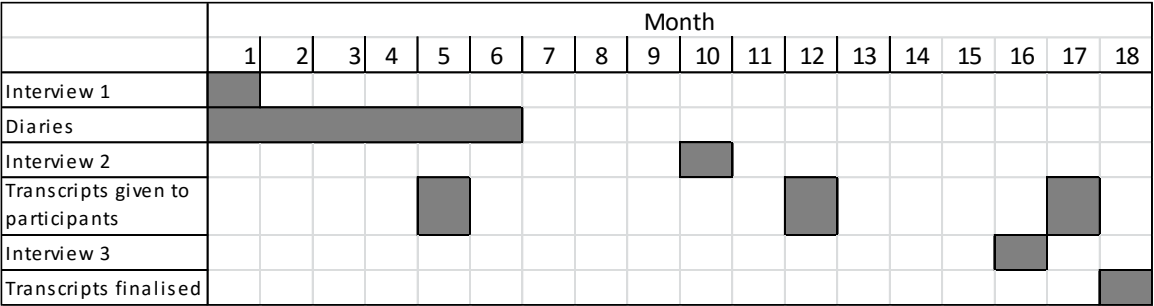


Figure 2: Actual interview timeline (for single interview)

The interviews took an appreciative enquiry approach, with broad, open-ended questions forming the backbone of the first interview, and a basis for subsequent discussion. The aim was for a narrative of experiences to emerge over the course of an hour or two, but for the movement of the interview to be guided by the participant. The participants had access to the initial questions before agreeing to take part; this access formed both a part of the consent process, and was a part of how the research will adhere to emancipatory principles. Between the first two interviews, participants were asked to keep a diary of their experiences, aiming for a few paragraphs of text per entry, on a bimonthly basis, although the format and frequency of entries were be

decided by the individual participants. Not all the participants chose to keep diaries, but those three that did provided a huge wealth of material.

The interviews themselves were not necessarily solely face-to-face; the reasons for this are twofold. Firstly, it was partly about accessibility, for myself as a research and for the participants – it may, for example, have been easier for participants to do a face-to-face interview one day, but an interview over Skype the next. Participants were informed of this possibility from the outset,¹¹⁵ and they were able to dictate their own access needs, choosing from the following possibilities for each session:

- Face-to-face interview in a location of their own choosing, where they feel most comfortable;
- Skype interview (which will be recorded);
- Email or instant messenger.

Face-to-face interviews could have included a British Sign Language (or other language) interpreter or any assistants/carers the participants wish to have with them, should they have needed or wished to do so. In the end, none of the participants required an interpreter, and only one was accompanied by their carer. Nonetheless, keeping these options on the table was important to me, in terms of making the

¹¹⁵ See Appendix 2, p.346.

interviews explicitly accessible from the outset, and also in terms of acknowledging the changeable nature of some disabilities.¹¹⁶

Each interview lasted between half an hour to two hours when done face to face or over Skype, with the second interview generally being the longest – email exchanges took place over a few days. The timings depended heavily on the needs and wishes of the individual participant, but as was intended, the second interview was based primarily on my initial analysis of the first interview and diary entries, with the participants' own reflections on the interview process becoming a part of the research, with their reflections on their earlier responses becoming a part of the narratives. The third interview was intended as a conclusion, to review what was said, and to confirm the participants were happy with the analysis as it stood. As a result, it was very brief – most participants chose to conclude over email, for the sake of conserving their energy.

At the same time as the fieldwork period, I kept a research diary, detailing my own reactions to both interviews and participants' diaries. The purpose of this was twofold: firstly, it helped to clarify my thought process, informing my questions for the

¹¹⁶ See p.203 on accessibility.

second and third interviews, and my thoughts for the analysis; some of this material was shown to participants (and they were given the opportunity to see the entries concerning them or the research in general at any point in the process). Secondly, the diary formed a part of my reflective process, in terms of both personal reflection, and my development as a researcher.

Participants were sourced through existing disability and/or BDSM networks, as well as personal contacts; these networks are online as well as face-to-face, and included social media such as Twitter and Facebook, as well as BDSM-focused network FetLife. All of these sources involved participants contacting me directly to express a wish to take part – the call for participants was available publicly (Sheppard, 2014a) rather than sent to individuals. A word-of-mouth snowballing effect was created, and potential participants were found fairly quickly, especially considering that it was impossible to give an estimate of how many potential participants there could be.

Research Ethics & Emancipatory Research

The research took a participatory and emancipatory approach that complemented existing radical and critical models of disability (Mercer, 2002). Emancipatory research into the lives of disabled people has the primary aim “to explore and de-construct

widespread and common-sense assumptions that disablement is the inevitable outcome of physical, sensory or cognitive impairments" (Barnes, 2009, p. 461), actively rejecting the Medical/Tragedy Model, and rooted in the Social Model of Disability.¹¹⁷

While Barnes (2009) reduces the Social Model to its very basic root in discussing the principles of emancipatory research, it is of course questionable whether if, in rejecting the Social Model as overly simplistic and inadequate to fully theorise impairment, we can still claim it as a position when designing research. Obviously, in my commitment to using the aims and principles of emancipatory research, I said (and continue to say) yes, but at the same time I continue to be aware of the difficulties and the inherent hypocrisy in doing so – and in trying to have the best of both worlds. In designing the research, I used the Social Model as a heuristic device to help understanding (Barnes, 2003) rather than the sum total of how disability and impairment are and should be understood; I took to heart Barnes' guideline that "emancipatory research should be judged upon whether it facilitates the self-empowerment of disabled people ... Here, empowerment and emancipation are used interchangeably and defined in terms of revealing social barriers, changing perceptions of disability, and generating political action" (Barnes, 2009, p. 463).

¹¹⁷ See p.46.

To begin with, I paid particular attention to Oliver's (1997) scaffolding for emancipatory research, with a focus towards the importance of improving the lives of disabled people, academic knowledge concerning those lives, and challenging existing paradigms around disability. When it came to choosing and developing a methodology, the social model, being of longer standing than crip theory, has a greater volume of guidelines on how to produce ethical research with and about disabled people, which should not be ignored; the basic framework for emancipatory research was developed not long after the social model itself, and, most particularly, was developed in partnership with disabled people (Barnes, 2009, 2003; Barnes *et al.*, 2002; Oliver, 1997; Priestly, 1997). However, much has changed since Oliver wrote the original guidelines in the 1990s – and, tied up with Barnes' observations on the role of market forces on research and misuse of research by policy-makers (2003), Goodley and Moore (2000) observed that, as the academy has accepted disability as a 'worthy' subject of research, researchers within the academy are often placed in positions that conflict with their desire to act as allies to disabled people; "it is disingenuous for researchers to advocate research and empowerment when they also seek scores in research assessment exercises that are, arguably, inversely related to prospects for empowerment" (Goodley and Moore, 2000, p. 875).

This conflict, while not always obvious, pushes forward the need for researchers engaging with disabled people to consider their own role. Crip theory, on the other hand, while lacking in a developed body of work that defines crip research methods, offers a political/relational understanding of disability, which aids a conception of research that takes into account that knowledge is positioned as a form of power (Erevelles, 2005; Foucault, 1998, 1973; Hughes, 2005), and that the researcher, in having specific *academic* knowledge, is positioned as powerful. This is especially true in contexts where being a part of an institution, whether academic or medical, taps into a discourse where the educated researcher or medic has knowledge of, and therefore power over, a disabled person's body (Erevelles, 2005; Hughes, 2005). Thus, a more crip approach to the method was needed, while I still made use of the original emancipatory research framework for its practical insights.

From the outset, this research would stretch the original scaffolding somewhat beyond its original purpose (even before bringing in a crip approach), in explicitly setting out to include people with chronic illnesses in the research, particularly given that until recently, Oliver (2013) argued against the inclusion of people living with chronic illness or chronic pain in disability. It is important to acknowledge Oliver's viewpoint – and that "modern movements for the rights of people with disabilities have fought the identification of disability with illness [in the belief that] ... This

identification contributes to the medicalization of disability ... [and] fosters the myth that people with disabilities are globally incapacitated, which in turn [also] contributes to the social devaluation of disabled people" (Wendell, 2001, p. 17); the social model approach fought hard to extract disabled people from institutionalisation at the hands of medicine, and the ongoing role of medicine and the dominance of medical diagnosis in whether or not someone is 'properly' disabled remains an issue.

However, as Wendell points out, "those of use with chronic illness do not fit most people's picture of disability. The paradigmatic person with a disability is healthy disabled and permanently and predictably impaired" (Wendell, 2001, p. 21); this makes it arguably easier – or perhaps safer – to focus on 'healthy disabled' people, rather than chronically ill people, whose needs are often variable, and may or may not 'get better'.¹¹⁸ At the same time, this exclusion of those with chronic illnesses is a gendered issue; women have a higher incidence of many chronic illnesses, and gaining recognition of such illnesses – and the subsequent needed assistance – is influenced by perceptions of, attitudes towards and judgements made because of, gender. For

¹¹⁸ While someone can recover from cancer, and my fibromyalgia may one day disappear, someone with MS or cerebral palsy may see their needs change over time; others' needs may vary from day to day. Being autistic, or having an amputated limb are all lifetime states and are not expected to change in the long term.

myself, then, including chronically ill people within the wider group is a threefold issue – firstly, a feminist one; secondly, a practical one, as many chronic illnesses include pain among their symptoms; thirdly, it is a personal one – as a chronically ill person myself, I have experienced what I can only identify as disableism, both in terms of physical barriers and attitudes.

This research, while using emancipatory principles, may not be considered ‘properly’ emancipatory in other ways; I am not including organised groups of disabled people in designing the research (Oliver, 1997). Although I would welcome their input, issues of sex and sexuality are, at the moment, further down the list of priorities for many disabled people’s organisations and charities, most of whom are concerned with the impact of the current political climate of austerity.¹¹⁹ However, as recent TV programmes such as *The Undateables* (Sewell, 2012), and the hundredth *Ouch!* Podcast (Crossan and Monaghan, 2013) have shown, sex and sexuality remain an issue for disabled people. The focus on user-led research and responding to the majority (particularly where DPOs are concerned) has led to research that is *normative* in its conception of sexuality, and in its conception disability itself (Tepper, 2000), and

¹¹⁹ And for many, quite rightly too - I would not for a moment like to suggest that the current political climate is anything other than a threat to disabled people’s lives.

excludes LGBTQ+¹²⁰ disabled people. This research aimed to challenge normative constructions of disability and sexuality, and hopefully break down those barriers which exclude some disabled people from wider communities.

Reflexivity and honest self-reflection play an important role in doing disability research, into sex/uality or not; accountability becomes difficult when Disabled People's Organisations (DPOs) are not necessarily interested in the proposed research due to its focus on non-normative sexuality, and, within the academy, "the use of formal tests of quality control ... has often hidden disablist assumptions that rarely acknowledge the specific circumstances of researching disability" (Barnes, 2009, p. 465). As a result, accountability lies with the researcher(s) and their participants; while the researcher can meet the ethical requirements of their institution, this may not satisfy a critically crip reading of how research can and should be done. Like the emancipatory research framework before it, a crip concerned with the power differential between researcher and participant; it takes a somewhat more detailed account of the imbalances (I would start with acknowledging that without the co-operation of disabled people as participants, little or no good research could take place, and thus the power differential is not entirely one-sided), and rather than attempt to wholly balance the scales, it acknowledges the specific circumstances of

¹²⁰ Lesbian, gay, bisexual, transgender, queer, and other gender/sexual minorities.

those imbalances, and seeks to draw them into the open.

For many, 'properly' emancipatory research should have a measurable, quantifiable and *positive* impact on politics or policy, or at least the aim of such an impact – it should intend to, if not actually, improve the lives of disabled people. And while I hope the research will have an impact, instead I used emancipatory principles in order to do *good* research, with an ethically sound approach to the research. This was in part because "research is not a zero-sum contest with one 'winner' and 'loser' ... oppressors and oppressed are not always easily distinguished across different social contexts. What benefits disabled people may not advance the interests of other oppressed groups. Participants are not always agreed on where their best interests lie. Nor does the failure to transform the lives of research participants necessarily preclude a lack of impact more widely" (Mercer, 2002, p. 238). A quantifiable impact is in itself problematic when the subject of research - the experience of pain - is so very *subjective* and qualitative; measureable impacts suffer from much the same problem. Improving the lives of disabled people is, again, problematic – who is to say their (our) lives have been improved? Myself, as the researcher, the participants – or a panel of other disabled people? *Improvement* can be quantified – one can become richer, have more accessible spaces – but it is also subjective; you and I might have very different ideas of how I lives could be improved, and thus we might never agree on how to

measure improvement. Should improvement – once we have agreed on its measurement – take place immediately? If improvement adversely affects the social situation of another oppressed group (leaving, for a moment, that one can be a member of both), is it still improvement? Improvement, like accountability, is not straightforward; it does not take place in a vacuum.

Power Imbalances & Reflexivity

One of the biggest issues with doing research with disabled people is the imbalances of power inherent in disability itself, and between researcher and researched. In approaching this, and acknowledging that in trying to do emancipatory disability research I must address these imbalances, I examined¹²¹ the importance of my own disability to my identity and sense of self. One of the ways this has impacted my research is in my linguistic choices, and my use of ‘disabled people’ and ‘people with learning disabilities’ over other terms.¹²² I have made the conscious decision not to use the phrase ‘suffers from’ in relation to specific impairments, instead using ‘lives with’ – a term I prefer myself, as to say that I ‘suffer from’ my chronic illness is to

¹²¹And continue to, as this is not a single activity, but an ongoing process.

¹²² See p.20 for more on language.

imply that I am an object of pity, and that my life is inherently lesser than those who are not sufferers.

My position as a disabled person – specifically as a person living with chronic illness – further complicates the imbalances of power in research; I uncomfortably straddle both worlds, aware that my disability places me at the margins of academia, as HESA statistics report that approximately 4.1% of academics in the UK are disabled (HESA, 2016), and have identified themselves as disabled to their employer – and as a result the actual percentage is likely to be higher. At the same time, this positioning can matter little to those on the outside looking in; an academic is still an academic. Thus, as the power differential in the relationship between researcher and participant lies – however much one tries to disguise it or redress it – with the researcher, and it remains up to the researcher to ensure that the research is carried out in an ethically sound manner. However, the nuances of the power differential can vary; for example, disabled researchers can be perceived as having an ‘in’ – as having an understanding of the experience of disability shared with the participants, but this relies on the researcher being visibly disabled, or outing themselves as disabled (Vernon, 1997). This can have a negative impact – internalised ableist attitudes held by participants can in fact make the research more difficult (Brown and Boardman, 2010; Kitchin, 2000), while disabled researchers can face discrimination from their academic

institution in ways that make acknowledging their disability a risk, especially when engaging in already risky sex/sexuality research. While I chose, and continue to choose, to make my disability an explicit part of my identity as a researcher, I only did so after a lengthy period of reflection, and while I think it has benefited me in terms of developing relationships with participants, as well as grounding my theoretical approaches, I cannot say that it will not have a negative impact in the future. To that end, while I may personally think that increased visibility of disabled academics is necessary to challenge institutional ableism, that self-same ableism makes visibility risky – and I cannot say that all disabled researchers should make the same decisions as I did; each must make the decision for themselves.

While the power may lie with the researcher, at least in terms of how ownership of knowledge is constructed, it is important to remember that participants have a singularly significant role – research relies upon them to participate, and it cannot be done without their ongoing consent and active participation. Put simply, as a researcher, I can ask as many questions as I like – but it is only with the participants' good will that I get answers. To that end, I believe that participants should be involved as much as possible in the research process – in order to feel a sense of ownership, in a way that acknowledges their emotional and physical investment in the research as it is carried out, and as it is presented to others.

Participant validation is the process of asking participants regularly if they were ok to continue taking part, ok to keep talking, or ok with what had been said thus far, as part of an on-going consent process. It is costly in terms of time and energy, but is, I have found, undoubtedly worth that cost. For myself, developing an ethically sound, accessible approach came down to two very simple questions: how would I want to be treated if positions were reversed, and how do I want my treatment of participants to be perceived? So much of my answers came down to the most basic of ethics – of basic human decency – crucially blurring the lines between subjectivity and objectivity; I could only work on the basis of how I, as a disabled person, would wish to be treated, and how I wanted my participants to view me and their participation. This is not to say that participants may not in fact wish to be treated differently (indeed, some probably found my continual ‘is this ok?’ more than a little irritating), but it focuses on the *humanness* of the participants – on working against previous research about disabled people that has tended to objectify them, to deny their agency and their knowledge (Barnes, 2003; Morris, 1992; Oliver, 1997; Priestly, 1997).

Acknowledging the benefits I will accrue through the research is also a part of doing emancipatory research (Priestly, 1997); I am fairly certain that, in taking the research as a sum, I stand to gain far more than the participants do – and far more personally

than disabled people across multiple communities (although I hope disability communities will benefit). This is, however, not reason not to do the research, but it does mean that there is an inevitable imbalance between my own position and that of participants; "it is inappropriate for researchers to consider disability research production as discrete from its social context" (Priestly, 1997, p. 89). This process of reflection is important, furthermore, because we cannot research oppression objectively (Oliver, 1997); even though my research does not have quantifiably political aims, it is still concerned with the lives of oppressed people, and the processes of their oppression – and the processes of my own oppression, and my own life; objectivity is therefore impossible, and indeed undesirable. At the same time, "the closer our subject matter to our own life and experience the more we can expect our own beliefs about the world to enter into and shape the very questions we pose and the interpretations we generate from our findings" (Vernon, 1997, p. 159). Morris, at the same time as acknowledging how personal experience shapes research, argues that this is important, whether those experiences were/are positive or negative (Morris, 1992); the personal as political is crucial to feminist emancipatory disability research.

In researching both disability and BDSM, having an 'in,' and being, if not 'one of us,' then a sympathetic ally, is important (Priestly, 1997; Weinberg, 2006). For BDSM,

having an 'in' is important even in making initial contact with prospective participants, as "with the possible exception of the largest metropolitan areas, heterosexual sadomasochistic groups are almost invisible. Even in the larger cities, SM groups are not easy to find or to study without a member who will vouch for the researcher" (Weinberg, 2006, p. 26). Having chosen to situate my research outside of disability community groups, I also situated my research outside of BDSM community groups, with the exception of one online community, which I used primarily as a way of spreading my call for participants through virtual message boards.¹²³ This was done partly because of my own, personal, discomfort with the BDSM scene – and not wishing to claim an association I did not have. For some BDSM practitioners, seeing the researcher as a sympathetic ally is important, due to the stigma that can come with 'being kinky';¹²⁴ practitioners do not, in general, want to further the discourse of BDSM as pathology, and may not want to speak to researchers who they feel will take this approach, just as disabled people may not want to speak to researchers who they feel will misrepresent them (Barnes, 2009). This overlapping experience of being objectified and pathologised – as well as the discomfort with researchers from outside the community – meant that I felt more comfortable bringing influences from disability into researching sex/uality, and vice versa.

¹²³ See p.182 for more on this.

¹²⁴ See p.158.

As a result of the risk of misrepresentation, it is important for research to consider how the research will impact the researched communities, at all stages of the research (Barker and Langdridge, 2009; Barnes, 2009; European Commission, 2010); "There is a responsibility, as a researcher, to try – as far as possible – to predict how the media and wider social world are likely to take up the accounts that are produced, especially when the sexualities we write about are largely silenced within available narratives" (Barker and Langdridge, 2009, p. 9). In the case of the proposed research, in looking at narratives around pain, it is possible that the research could be used – could be misrepresented by others as – supporting the continuing pathologisation of BDSM, and "it is vital that academics are very cautious when reporting narratives which have the potential to exacerbate, rather than ameliorate, the precarious position of sexual communities in wider culture" (Barker, 2013). Running alongside the pathologising of BDSM is the narrative within the BDSM community that BDSM practices are in some way 'healing' various ailments, such as pain or psychological trauma (Barker *et al.*, 2007). This narrative possibly as damaging as viewing BDSM as pathology; the two discourses are intertwined, both seeing impairment or trauma at the root of engaging with BDSM, only differing in whether or not that engagement is a positive or negative act. I am obviously cautious about this narrative being supported through the research, however, I would argue that silencing this story in otherwise supportive research is *also* damaging, as narratives cannot be explored, and judged as

‘good’ stories to hear until they have been heard (Sheppard, 2012).

Accessibility

Accessibility plays a significant role in making research emancipatory; it is important to me as a disabled person that the research process is accessible to myself, but also in terms of participants and audience – the research process must be accessible to participants, and the findings should be accessible to both participants and wider disability communities. In looking at making my research accessible, it is important to consider what ‘accessible’ means in both global and local terms (McRuer, 2006; Wendell, 1996); access is a broad notion, as well as culturally, socially, spatially and temporally specific. Access can be constituted through various adaptations, and it is important to consider that what makes something accessible to one person may make it *less* accessible to another.¹²⁵ It is important to focus “on the normative commitments that engaging in a dialogue imposes on the participants” (European Commission, 2010, p. 27); at the same time, considering accessibility is part of a critically disabled and critically queer positioning – challenging and transforming “the

¹²⁵ For example, using a BSL interpreter to assist a D/deaf person only works if the person is themselves as BSL speaker.

substantive, material uses to which queer/disabled existence has been put by a system of compulsory able-bodiedness, about insisting that such a system is never as good as it gets" (McRuer, 2006, p. 35). As such, I would position adaptations as a central part of the practical aspect of doing research, with the intent that having these provisions in place is not a part of a 'tick-box exercise' of diversity, but in fact how research is and should be done – such that removing adaptations for a non-disabled participant should become the new adaptation, as it were. This adaptive approach to research practice, and any theorising of disability, involves an awareness of the situational nature of disability, and, to borrow from the concept of debility, how social practices and environments can act as barriers, or increase the effects of a disability (Kafer, 2013; Puar, 2009). Like the reflexive self-examination which influenced the earlier section, while it is possible to devote a few pages to discussing the topic before ignoring it, it was more important for me to lace accessibility throughout the research, from the design of the methodology, to carrying out the research, to the dissemination and publication of the results and any connected work; I have focused here on accessibility, but return to it later.¹²⁶

For disabled researchers like myself, I am forced to take the time to consider how I wish to treat *myself*, to consider how I will do research in a way that treats my health

¹²⁶ See p.182 for how the research was structured.

and my energy as a valuable, valid, resource. Much of this, however, comes down to a balancing act, deciding between how to do research which will be respected, in the perceived 'right' way, doing research in a way that is practical and achievable, and doing research in a way that addresses the power imbalance between researcher and participant. It is also important to consider that "disabled researchers nevertheless undertake research in context where disability is assigned meanings disabled people may not share. [Brown and Boardman] argue that *all* researchers should attend to their own 'bodily signifiers' (whether in relation to ethnicity, wealth, gender, age etc.) and embodied experiences of research processes, as these are integral to research outcomes, the ethics of research, and are a means by which to address power differentials between researcher and participant" (Brown and Boardman, 2010, p. 24).

Taking this reflexive approach affected my own research design in a number of ways – firstly through the perquisite of an honest assessment how my disability and non-research commitments impact my ability to do research. For example, I could not do two interviews in two days if one or both require more than two hours of travel, or lasted longer than a few hours each – the time and energy devoted to travelling with equipment, to listening, to the on-the-go analysis needed to ask questions all adds up into a high energy output for myself.¹²⁷ Taking time, researching slowly, can be as

¹²⁷ My disability restricts how much energy I have - while also resulting in even the most basic of tasks

much a political statement as a necessity (Ahmed, 2014; Chen, 2014), working against the neoliberal discourse of ever-increasing speed and flexibility.

If interviewing is physically and emotionally draining for the researcher, it must also be so for participants – particularly participants with illnesses or disabilities that limit their energy. An acknowledgment of the energy participants are putting into taking part is important – particularly given that there is not always a quantifiable, direct reward for their taking part (unless there is a financial reward, which muddies issues of consent). A sense of shared ownership, and an explicit placing of the power of consent in the hands of participants can increase their feeling of having done something positive for others through participating – and as this is often the only reward we can offer, it should be acknowledged and foregrounded.

Within this research, while my focus has been on chronic pain, which is often accompanied by mobility issues, the participants themselves have had a wide range of impairments and access needs. It is important to consider that access is not always

using more energy. As a result, I have to carefully budget my energy by managing and planning what tasks I carry out in the course of a day, or over a period of weeks. This is almost as much fun as it sounds.

straightforward, and a varying range of needs should be acknowledged and prepared for – and an awareness while planning that potential participants can have multiple disabilities with different access needs and preferences. For example, while none of my eventual participants needed a sign language interpreter, in making it obvious that I was willing and able to meet this need,¹²⁸ I was able to *explicitly* include people who might otherwise have felt excluded – this both widens the cast of my net as I search for participants, but also foregrounds my awareness of the nuances of access. In choosing to make my ability to meet access needs explicit within requests for participants (and also when communicating with participants prior to interview), I made my intent to be inclusive more explicit; for so many disabled people, myself included, the assumption is that *inaccessibility* will be the order of the day - an order I wished to challenge.

The interviews themselves were or could have been made accessible in a number of ways; some of those I never needed, but I maintain that making the initial preparations for the *possibility* of them being needed – and explicitly stating that such preparations have been made – is worth the time and effort due to the dual rewards of being inclusive, and then of being able to accommodate a participant. Firstly, some

¹²⁸ See Appendix 2, p.365.

disabled people have an assistant or carer, who supports¹²⁹ them in a range of ways; the disabled person was able to have their assistant present during the interview should they have wished. The assistant's presence may have been practically helpful, but may also have helped the participant to feel comfortable – redressing the imbalance of power between researcher and participant through simple numbers. At the same time, the participant may have felt constrained by the presence of their carer, especially when discussing sex or sexuality in cases where they are aware that their carer does not approve of or support their sexuality or practices (Earle, 1999). The decision to have their assistant or carer present remained with the participant, but I then needed to consider their consent to be present – and how they present a challenge to confidentiality. I prepared consent forms for carers or personal assistants,¹³⁰ which explicitly stated the need for confidentiality, and was prepared to discuss this with both participants and assistants/carers as needed. In the end, this was only needed in one case,¹³¹ and this alone made it more than worth the relatively small amount of time required to prepare the consent forms even before the participant in question joined.

¹²⁹ This role may be paid, but may be performed unpaid by a family member or friend. Within this particular context the financial aspect is not particularly relevant, but it should nonetheless be noted, and can be explored.

¹³⁰ See Appendix 6, p.380.

¹³¹ See participant profile on p.229.

Secondly, I took a mixed-mediums¹³² approach to interviewing, combining face-to-face interviews with email and Skype calls. The methods through which participants recorded their diaries were also open to adaptation, and they were welcome to make entries in whichever way suited them.¹³³ The possibilities of internet-based video calls, email, and instant messaging are obvious, although all are tempered by the problems of accessibility, in that disabled people are more likely to not have access to a computer and the internet at home (Pilling *et al.* 2004). It has been noted that participants tend to be more focused and honest when interviewed over email (McCoyd and Schwaber Kerson, 2006); in addition, participants have the time to consider their responses, and answer at their own pace, when a discussion is carried out through an exchange of emails – there is no longer the time pressure of an immediate response for participant or researcher. For other participants, for example with variable impairments or who have issues with anxiety, this lessens the demands on them from the outset – and for disabled researchers, it can have largely the same

¹³² This could be referred to as a mixed-methods approach, depending on whether you consider interviewing by email as a different method to interviewing face-to-face, or a difference of communication medium.

¹³³ See p.182 for more on the structure of the research, and Appendix 5 on p.380 for the diary suggestions given to participants.

effect. Email, instant messenger, and video calls have another benefit to both participants and researchers – they do not require travelling. As well as saving money and being more favourable in a risk assessment, for people with limited energy, being able to sit in comfort, at home, makes an interview much more accessible – but still presents the researcher with a wealth of data. While this approach presents conflicts – such as the discomfort felt by those who choose a public, face-to-face interview versus the comfort of those who email, or the discomfort of those who are not familiar with the technology of Skype calls – it is still possible to see how accessibility makes such conflict a necessity.

In all of these accessible adaptations, the key aspect is time – time to write a longer explanation, time to discuss the process, time to plan and make arrangements for interviews, and time to take longer to do interviews and discuss those interviews with participants. However, much like any other pre-planned event, time taken at the early stages, in preparation, can lead to a much more enriching interview process, on both parts. And, more selfishly, it allows a disabled researcher time – it acknowledges that, for many, a disabled life is a life lived more slowly (Kafer, 2013; Wendell, 1996). This acknowledgment of the time needed to be disabled forms, for myself, a large part of my critically crip approach to research – moving the strictures of emancipatory social model research into a crip arena, a critically crip approach interrogates what it means

to be disabled, for others and for myself (Kafer, 2013; McRuer, 2006). This approach enabled a more free-flowing and adaptable approach to attempting to balance the unequal relationship between researcher and participants – while remaining aware that the relationship can never be wholly balanced, due to power dynamics of multiple, intersecting identities, roles, and agencies (Barker, 2013; Deckha, 2011; Downing, 2012).

Narratives

The research consisted of exploring narratives and discursive constructions of pain. The narratives were gathered through a series of interviews, diary-keeping, and discussions between myself and the participants; the transcripts of the each interview and resulting notes were sent to participants to review, and after the second interviews were complete, I used Nvivo to code the transcripts and notes from all the interviews and diaries (see Figure below). I then used a critical narrative analysis to interrogate the interviews and discussions, focusing on "identifying narratives and examining them for function and tone as well as their thematic content ... [This is done alongside] ... imaginative hermeneutics of suspicion to interrogate [my] own way of viewing the topic and the narratives being employed by the participants"

(Langdridge, 2007b, p. 56); this produced a series of themes which went on to form the analysis chapters. The critical narrative analysis was used to explore how the narratives reinforce or disrupt existing discourses around pain, disability, impairment and sexuality, and if – how – theoretical understandings of pain and impairment need to be changed. In this way, giving a space for certain voices and stories to be heard is an important part of disability research that aims to be emancipatory, as providing a space for a transgressive movement that is necessary to being the process towards a complete sexual citizenship (Langdridge and Butt, 2004) for disabled people.¹³⁴

Hermeneutics of suspicion falls under the broader umbrella of Interpretive Phenomenological Analysis, “an approach intended to explore how participants experiences their world, and hence enables an insider's perspective of the topic under study. The process of analysis derives themes of categories from the data itself, rather than categorizing data on the basis of pre-defined categories” (Murray, 2004, p. 966). Hermeneutics of suspicion, in critically examining narratives, places both participants and researcher within broader sociocultural discourses; it is important, however, to remember that the interpretive claims I make regarding the narratives will depend on my own situation and context (European Commission, 2010). This is because social

¹³⁴ Exploring and improving sexual citizenship for disabled people is beyond the scope of the proposed research.

relationships and flows of power affect the narratives that are told, and "research accounts cannot simply be understood as direct copies of an assumed reality ... [sexual stories] can no longer be taken as transparent and unproblematic in their search for truth. Instead, the social scientist is part of the very process being observed, analysed and written about: I am part of this process and it is deeply social" (Plummer, 1995, p. 12).

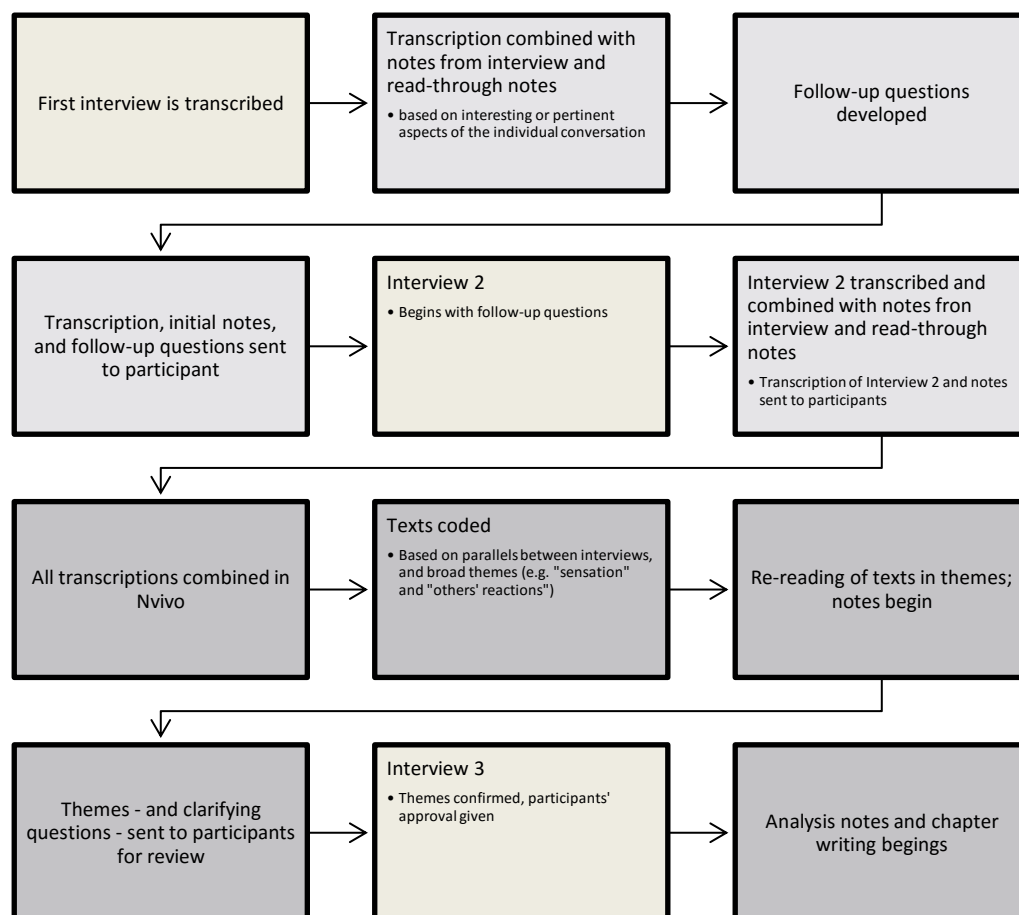


Figure 3: Flow of analysis process, from first interview to analysis writing

At the same time as taking an emancipatory approach towards the research as a whole, I also took a sex critical position (Barker, 2013; Downing, 2012) towards BDSM and erotic pain, as a part of both interrogating narratives and reading critically. This approach interrogates both narratives and the sociocultural context of those narratives, as well as the body as both subject and object (Grosz, 1994). A sex critical position does this through "[rejecting] the neo-liberal choice rhetoric, and [acknowledging] the multiple intersecting power dynamics within which agency operates" (Barker, 2013, p. 905). Narratives exist within, reflect, and shape flows of power, and "those stories that will be most readily said and heard will be those which facilitate standard gender divisions and the paramountcy of heterosexual relations" (Plummer, 1995, p. 31). A sex critical approach acknowledges the ways in which power affects sexuality and sex, and how disability and ableism interact with sex and sexuality.

Flows of power are also spatially and temporally specific, and as a result, I also applied the postcolonial feminist approach of 'world-travelling' to understand both disability and BDSM, acknowledging that there are communities and subcultures around both. World-travelling is a "critical yet respectful stance of listening to Others from cultural contexts not our own ... [It] readily affirms the situatedness and embodiedness of all

knowledge-making, ... [denying] the possibility of a pure or innocent 'equal' exchange between relatively privileged and marginalized locations, despite the best intentions we may hold as privileged subjects of undoing hegemonies that mediate our interactions with Others" (Deckha, 2011, p. 134). This involves taking three steps when examining a particular practice, such as receiving pain within BDSM play; firstly, to examine one's own culture's history for examples of the practice, or similar practices. Secondly, one searches for parallel practices – Gunning (1991) draws parallels between female genital cutting¹³⁵ and plastic surgery – before, finally, realising one's own hegemonic positioning and how one's positioning is rooted in, and may be continuing, colonial practices (Deckha, 2011; Gunning, 1991).

This approach informed my intent to take a critical but appreciative approach – understanding that my experiences and situation are not those of my participants, and therefore I may interpret their narratives differently. It particularly informed my decision to show participants my notes and explain my understandings, in order for them to speak back to me, as the researcher, about my findings. In using¹³⁶ the

¹³⁵ Also known as FGM (female genital mutilation) and female circumcision, although these terms are less accurate in terms of the processes performed.

¹³⁶ And, to return to the issue of power relations and what I'm getting out of the research, I am *using* their narratives.

narratives – and therefore voices – of disabled people, I hoped to place the narratives told under the control of the participants, to a certain degree, in that they were able to choose what to reveal, what to place importance upon, and how to tell their story. Participants were also given the opportunity to discuss the initial analysis of their own narratives, as stated above. This did not assume particular in-depth theoretical knowledge, but rather presented the collected transcripts along with my initial notes – more along the lines of ‘A refers to event X several times; importance of emotion here.’ This gave participants the opportunity to feed back on the conversation as a whole, correct any mistakes, and point out where they thought I was wrong (or right). This acknowledged that disabled people are not passive research subjects, and aimed to involve participants more fully in the research process and make the process more transparent.

Consent

The approach I took to informed consent is very similar, in broad terms, to the concept of risk-aware consent, which originates in BDSM communities (to replace the outdated “safe, sane and consensual” (Barker, 2013)). This, to me, means respecting the autonomy, dignity and the self of persons involved (European Commission, 2010), but also respecting that individuals are capable of judging what they are able to do –

and will know what they are capable of consenting to. At the same time, consent is an ongoing process, and I repeatedly checked for consent throughout the interview process. While capability and vulnerability is a complex issue (Goodley, 2014; Rogers, 2009), in this case I specifically excluded individuals with 'severe'¹³⁷ learning disabilities, because I felt that I was personally ill-equipped to deal with these issues at the start of the research (mostly through my own inexperience), and thus I was unable to adequately include their experiences. This is not, however, to say that individuals with severe cognitive and intellectual impairment cannot or should not have sex, or even engage in sexual practices that could be categorized as BDSM – it is simply that I was personally ill-equipped to deal with the intersecting issues therein. I had no wish to do more harm to wider views on non-normative sexualities, consent, and intellectual impairment by trampling in willy-nilly into an area where I was effectively a layperson. None of my participants identified as having learning disabilities that could have impacted their ability to consent, and at no point in any of the interviews – or during my reflection on them – did I have reason to question participants' ability to consent, to sex or to participation.

¹³⁷ Severe, here, means that individuals have "significant limitations both in intellectual functioning and in adaptive behaviour as expressed in conceptual, social, and practical adaptive skills" (Education Queensland, 2012).

The notion of informed consent that I used was that participants needed to be as aware as possible of the processes involved, and the intention of the researcher(s). This is added to by the use of a notion from the BDSM and alternative sexualities scene (as well as ‘pro-sex’ feminism) – that of ‘risk-aware consent,’ along with the movement towards creating “cultures of enthusiastic consent and/or taking mutual responsibility for creating dynamics and situations in which consent is possible ... [where consent is] a relational dialogue” (Barker, 2013, pp. 9–10). Risk-aware consent involves, for me, making participants aware of my aims and intent, both specifically and in a wider socio-political context, in order for them to decide for themselves if they wish to enable the research through participation – and if the potential risks¹³⁸ are outweighed by the possible benefits, given that they will not benefit directly beyond a cup of tea and the warm glow of having helped someone else do something.

Consent, here, is a balance of the formal consent agreement, and the provision of written or recorded information, along with a process of ongoing verbal checks – pausing during interviews to ask ‘are you ok?’ even when the participant doesn’t appear to be distressed, as well as checking occasionally to ensure that they aren’t baffled by why you’re asking particular questions. Much of this process is made up of

¹³⁸ Whether that is by being distressed due to the discussion, the outlay of energy required, or the act of ‘coming out’ (again) as disabled or queer, discussing one’s experiences is risky.

soft interview skills – but it is nonetheless something that needs to be explicitly discussed. Participants may also feel that, once they have given written consent, that withdrawing consent is ‘being difficult’ (especially participants who have previously been socialised to not ‘make a fuss,’ or who are used to their needs and emotions being ignored) – and giving them an explicit space within the research process to call for a break, express discomfort, or indeed, withdraw, is a necessary part of an ongoing, relational process of consent. Checking in after the interview is the last part of this process – I advocate sharing transcripts with participants, as a formal, final check for consent, as well as a more informal, friendly check in. In a case where the interview was long and particularly emotionally charged, this meant that I’d satisfied my own fears that my questioning had upset the participant, but also helped me develop my understanding of the participant’s life by taking a little longer to get to know them outside of the formal interview situation. In situations such as research into disability and sex/uality, both of which are deeply personal experiences, the interview is a personal process for myself as well as the participants – and taking time to check in helps to acknowledge this.

As a part of this, I also gave potential participants a few days’ time (at least) between giving them the consent information sheet and asking for consent (Hunter, in press). I

gave as much information in possible in the brief call for participants,¹³⁹ with pre-prepared information available to those who express interest in participating. I used a public blog where this information was to be freely available; this was used in conjunction with other public online social networks to source participants.

Informed Consent

Informed consent plays an important role in access – and in making the research emancipatory, in making the research process as transparent as possible from start to finish (Barnes, 2009); I made it clear to potential participants *how* information was going to be used, so participants could choose what to reveal (European Commission, 2010). To do this, I used accessible, straightforward language, and also encouraged potential participants to ask questions. This process seems, at first, to be rather more complex than it in fact is – instead it is making the participants as fully aware as possible of the process of the research, including aims, timeframe, and their rights as participants. In explaining these processes in everyday language to potential participants – and inviting them to ask questions and critique the work – I enabled them to consent in an informed manner, while also being open and welcoming, rather

¹³⁹ See Call for Participants on p.365.

than preserving a tidy delineation between layperson and academic, acknowledging that non-academic knowledge is valid and valuable – and indeed the knowledge of participants is needed for research to go ahead.

This approach was originally developed in response to my perception that I needed to open my research process up to critique by disabled people – in an attempt to meet Oliver’s requirement that emancipatory research be developed in conjunction with disabled people’s organisations (Oliver, 1997). This not being possible when groups are uninterested – or when giving control over the research to one group would be restrictive – it seemed an obvious solution. However, I quickly discovered that it also acted to make my research and my position as a researcher more accessible in terms of adjusting the power differential – in making me more approachable, and the research purpose clearer.¹⁴⁰ It also made both myself and my participants happier and more comfortable – a key aspect of any conversation about sex.

It can, of course, be argued that using clear, straightforward language to make clear the intent of the research is ethical practice when engaging with *any* community; this

¹⁴⁰ This may also help in situations where participants and researchers do not share the same first language – which, while it did not come up in the fieldwork, was nonetheless a necessary consideration.

remains true. However, when engaging with a community that have for so long been objectified and excluded by research and researchers, being straightforward is particularly important when engaging with disabled people. It is also worth considering that communities of disabled people include people with learning difficulties, and people with impairments that affect their cognitive function; even if the research project doesn't include them explicitly, it is worth considering how to include them.

I prepared an information sheet,¹⁴¹ which included not only the initial research questions, the purpose of the research, and the interview format, but also:

How information was kept confidential and anonymised

This acknowledged that anonymity may be hard (if not impossible) within small sub-groups (European Commission, 2010), as may well happen here, especially as I sourced participants through word-of-mouth. This impacts – and is impacted by – the importance in having an ‘in’ for this research,¹⁴² and in being a part of the communities involved; the trust shown to the researcher, by participants, impacts

¹⁴¹ See Appendix 3, p.371.

¹⁴² See pp.197, 200.

more than just the relationship between participant and researcher. However, the "the default position [was] that all information presenting in the research setting [was] treated as if it were subject to the duty of confidentiality" (European Commission, 2010, p. 80); the only people who had access to the full recordings and transcripts were myself, my supervisors, and a professional transcriber. Participants were made aware of the risks of incomplete anonymity. All participants were assigned a pseudonym, unless they expressed a wish otherwise, and the profiles¹⁴³ were written to give only minimal detail. Participants were able to choose whether or not their diagnoses were included, and the profiles all met their approval.

Participant control

Participants were given the choice of anonymity¹⁴⁴ (as they may not wish to be anonymous), and a degree of control over their data, such as the choice to remove parts of the interview from the transcript, and hence from the research – they were asked to read over their transcripts and a profile of themselves, and asked if they feel comfortable with what it reveals about them, and how I interpreted their narratives, especially in the early stages of the analysis. It was expected, and thus made clear from the beginning that there would be a time-limit of two months from receiving the

¹⁴³ See p.226.

¹⁴⁴ And the choice of what *nom de research* they wish to be identified by.

final transcript for participants to bring up any changes, but that I would also give the participants notice when I felt that making further changes would be impossible. In the end, participants were informed of the final date of submission, and the point at which they would be unable to make changes – and for a couple of participants, this was only a few weeks after the third interview.

If participants wished to have, or required, interpreters, personal assistants, or carers to be present during the interview, there were separate information sheets and consent forms for them,¹⁴⁵ but their involvement would have been controlled by the participant. They would have been asked to respect the autonomy of the participant in deciding to take part in the research, and to uphold the same confidentiality as myself, although they would be free to discuss the research with the person they assist, should they both wish to do so. I would have done my best to ensure that interpreters were aware of what is being discussed and were willing to take part. In order to overcome a potential barrier to participation, I made it clear that I would be meeting the cost of any interpreters required.¹⁴⁶ However, none of the participants required interpreters, and only one required an assistant present.

¹⁴⁵ See Appendix 6, p.383.

¹⁴⁶ Assistants and carers, however, are already employed by the participant.

Who saw what?

It is important to note that, besides myself, others did have access to the participants' data – particularly my supervisors, but also a professional paid transcriber, who assisted with writing up the transcripts (this falls under the category of my own access needs). Both supervisors and transcriber were held to the same standard of confidentiality as myself. Participants were free to see their own transcripts and my notes on those transcripts, but not those of other participants.

How data was stored

In order to keep the data secure, especially when it came to personal details and complete transcripts, recordings and transcripts were kept on password-protected hard drives, with cloud-based storage as backup.

Minimising Risk

The research was not intended as harmful, and there was no intent to distress participants, although it is a sensitive subject. To that end, I had a list of BDSM and/or queer-friendly therapists and counselling services available to participants;

participants were of course able to stop the interviews at any time, and, as previously stated, I checked for consent throughout the interviews and discussions. As a part of gaining ethical clearance for the proposed research, I carried out a risk assessment; the results of which are laid out in Appendix 1 on p.361.

Participant Profiles

Natalie

Natalie is a white British cis-woman in her early 30s, with Myalgic Encephamylopathy (ME).¹⁴⁷ She identifies as bisexual or pansexual, and is married to a man, who is also disabled. They act as each other's carers, with further help from friends and family. She has had ME since her teens, and did not finish secondary school. She is from, and lives now, in the South East of England. Our first interview was carried out over email, the second by Skype, and the third by email. Deborah did not write diaries, but emailed me between the first and second interviews to discuss events and points she felt were important.

¹⁴⁷ This is also known as Chronic Fatigue Syndrome, and thus the acronym becomes ME/CFS.

Catherine

Catherine is a cis-gender but gender-questioning white woman in her early thirties, living in the South-East, where she also grew up; she has a post-graduate level education and is currently working. She has multiple impairments (specifically: Ehlers-Danlos, fibromyalgia, and Asperger's syndrome). She is married to a non-gendered person, and her partner is the first person she has explored kink with.

Julie

Julie is a white cis-woman in her mid-twenties, living in the southeast of England. She is bisexual and has been into BDSM since her early twenties. She has POTS (Postural Orthostatic Tachycardia syndrome) and fibromyalgia, both of which developed in her late teens/early 20s. She has a regular play partner, and at the time of the first interview, several semi-regular play partners; she also plays with others at BDSM clubs. However, this changed to a single regular partner, with much less play in her life, as her impairments resulted in her being increasingly restricted to her house and her bed between the first and second interviews. She has a postgraduate-level education, and while she was in employment at the start of her interview series, she stopped working after the first. Julie's first interview was conducted over Skype, and her second and third over email; she kept diaries which she emailed to me.

Charlie

Charlie is a non-gendered, genderfluid, trans, male person, in their mid-40s, living in the south east of England. They are of mostly European racial heritage, and have a mixed ethnicity. They identify as queer and as a switch, and are not currently in a conventional relationship, although they have lovers/play partners. They live with chronic pain, nerve damage, and a mobility impairment resulting from an injury over 20 years ago, as well as arthritis, Chronic Fatigue Syndrome and an associated Pain Syndrome, and autism. They are currently not in a position to work. They have been actively involved in BDSM since their 20s. Our first and second interviews were carried out face-to-face, and they kept diaries which we discussed, but that they preferred to keep private.

David

David is a white, heteroflexible cis-man in his late thirties. He lives in the east of England, and he is not working due to his disability. He has chronic pain due to damaged cartilage in both knees, as well as the after-effects of a traffic accident several years previously; he is also autistic, and has dyspraxia. He has been engaged in kink since his early twenties, and is mainly a top, although he is exploring bottoming. He is active in his local scene. He is in a poly relationship with a woman. All three interviews were conducted by Skype, and David chose not to keep diaries.

Michelle

Michelle is in their late 20s, and is trans*/genderfluid, polysexual, and a switch. They prefer the pronouns they/their. They are of dual heritage, and at the time of the first interview were living in the South East of the UK. They are in a poly relationship, with one primary partner and 2-3 other partners. They have Asperger's, a chronic pain and fatigue condition diagnosed as fibromyalgia several years previously (although at the time of the interview, that diagnosis was in question). They also have chronic pain resulting from adjusting to surgery to correct being born with legs of different lengths. They have a university education, but do not currently work, although they do volunteer. They were raised in a religious household but no longer practice that religion. The first interview was face-to-face, and they decided to stop at that point due to ill health.

Edward

Edward is a white, cis-man in his mid-forties. He has multiple sclerosis, and has used a wheelchair for the last twelve years. He identifies his pain as intermittent. At the time of the first interview he was in an exclusive Mistress/slave relationship with a dominant woman, and identifies as straight (although he will play with men). He has a postgraduate-level education and is employed. He lives in the south-east of the UK.

The first interview was conducted face-to-face, and he emailed diary entries to me.

Edward stopped his participation after delaying the second interview, after the end of his relationship.

Rita

Rita is a white cis-woman living in a small city in the midlands. In her mid-30s, she is a university graduate who does not work. She identified as having multiple impairments that included diagnoses of ME, hypermobility, PTSD,¹⁴⁸ and ulcerative colitis. She lives with her long-term partner, who was present for the first interview. She identifies as bisexual and as a switch with submissive leanings; both she and her partner play with others. The first interview was conducted face-to-face, but after that she chose to stop her participation.

¹⁴⁸ Post-Traumatic Stress Disorder.

Chapter Five: Crip Time

In dividing pain up into chronic and acute, based squarely on temporal terminology, orientated in time towards a normative construction of prognosis and expected recovery, pain is divided into ‘normal’ and ‘abnormal.’ While any pain can be regarded as abnormal – in that having no pain and thus being ‘healthy’ is the normal ideal, and pain is regarded as unwanted¹⁴⁹ or presumed to be the result of injury¹⁵⁰ – the experience of acute pain is a normal event, something all people are presumed to have had. Chronic pain, on the other hand, is *always* wholly abnormal. As this section will show, while in a strictly medical setting, the focus on time is concentrated on dividing the experience of pain into chronic or acute, and there is an assumption that experience of pain is the same as it was when the pain was first felt, when the pain was diagnostically useful or could be regarded as acute – thus chronic pain is cast as a repetition, saying or doing nothing useful or meaningful.

At a practical level a diagnosis of chronic pain (or another condition, illness, or impairment that includes chronic pain) takes time – sometimes months, sometimes

¹⁴⁹ See p.85.

¹⁵⁰ See p.81.

years – to be confirmed by medical professionals. After diagnosis – and sometimes before – more time is needed to access specialist medics, to find appropriate specialist care or medication. This lengthy process, firmly situated in the medical sphere, continually reinforces pain as medical, even as medicine may have little to say about chronic pain. Throughout this, the phenomenological experience of pain – how it feels, how those living with chronic pain experience it – is assumed to be the same. This is, as I will demonstrate, not the case – and the relationship between time and pain is far more complex.

This chapter will show that existing considerations of crip time, which as described in chapter one¹⁵¹ are inadequate in that they focus exclusively on the experience of disability in terms of pace of life relating to others. Crip time includes a huge range of ways of thinking about times, and ways of performing in time, that are affected by the composition, comportment, and capacities of the disabled individual's bodymind. When it comes to living with chronic pain, the notion of crip time provides a fertile ground for thinking through the experience of living with chronic pain over months and years, and the relationship between time and pain. Expanding notions of crip time to include experiences of becoming crip – of becoming used to, and accepting of, acquired disability, as well as developing a positive crip identity - can thus explore the

¹⁵¹ See p.73.

tensions between the normal and the crip, rather than viewing crip as wholly separate from – or opposite to – normal. The contestatory nature of crip destabilises normative notions of time, but also leaves space for ways of being in time – and moving through time – which are less than distinctly crip, which include more normative-seeming ways of being/moving. As being crip can also be understood as *becoming* crip – a process rather than a fixed state, notions of crip time need to have space to include ways of being/moving that are both normative and crip *within the same bodymind* - thus, while some aspects of an individual's ways of being/moving may appear distinctly crip, they may also perform distinctly normative ways of being/moving. In addition, performing normative ways of being in/moving through time may be an important part of an individual's acceptance of their bodymind, a part of their becoming crip, in that they are finding spaces for their bodymind – spaces in which they can feel positively, negatively, neither and both – and perhaps crippling normative ways of being in/moving through time.

In this chapter, I demonstrate how crip time can be expanded to explore the pace of life, its acceleration under neoliberal regimes, and how disabled lives can present as slow and unreliable lives – or a need for a slow life, and as ways of doing and thinking slowly (Goodley, 2014; Hickey-Moody, 2015), and as ways of responding to an unreliable bodymind. Conceiving of crip time as a space for unreliability recognises the possibilities and impossibility of the crip bodymind, while also demonstrating how

normative discourses privilege a narrow range of capacities. Acknowledging slow and unreliable lives “is a way of valuing how ‘disabled’ bodies and subjectivities experience and reproduce the world. Implicit in this suggestion is the belief that disabled [bodeminds] and embodied subjectivities experience and reproduce the world in ways that show up limits in popular sensory and spatial geographies” (Hickey-Moody, 2015, p. 140). Slow and unreliable lives demonstrate how the demands of a normative pace of life are, in many cases, simply normative *demands*, rather than necessities. However, *crip time* is not always slow – as Price points out, it can also be “accelerated to a terrifying cadence” (Price, 2015, p. 273) in times of crisis.

In addition, *crip time* can include time for diagnosis and prognosis, pace of development of bodily skills (such as walking, continence, or talking) and the normative rejection of a disabled future¹⁵². As this chapter will demonstrate, *crip time* in the context of chronic pain includes other aspects of living, particularly the time needed to manage disability, and the reliably unreliable bodymind, to think and do slowly, and to live at a pace that reduces the chance of unwanted or unchosen pain events.

¹⁵² See p.76.

Crip time as time to be unreliable

It is impossible to be in chronic pain and also to maintain a state of constant distress; the reliably unreliable body cannot be forever shut off from the world. Even beyond the need to communicate pain, the participants' narratives all told of a need to continue, to function in the world, to be and to do, while also acknowledging their pain and vulnerabilities. Living with chronic pain changes the lifeworld, but it does not end it. The world may be smaller, the possibilities fewer, the agency further constrained, but life does not end; the phenomenological self continues. Catherine and Julie have found that, over time, their chronic pain has not lessened, but it draws less of their focus; they are able to continue on, to live. As Catherine put it:

"At the beginning of my illness, I was constantly aware of this same level of pain, but as I sort of got used to it, I stopped being consciously aware..."

Although there are often signs that I'm unconsciously aware - I'll be moody or snappy or tired. Then some days it's more like, I'm aware of it, but can push it to the background" (Catherine, interview 2)

Moodiness and snappiness – and tiredness – are subjective, requiring us to regard ourselves as we would observe another's emotional expression; Catherine is speaking as much of how she expects others to read her emotional expression as she is of her own emotions, ascribing them negative (and gendered) descriptors. Her emotional

expression may be due to pain, but it is also due to the difficulty of performing as normal, of performing as pain-free; it is not solely an expression of pain, because she has learnt not to speak of her pain, not to let her pain show - and instead it escapes in the cracks of tone and choice of words, in incremental adjustments to get as close to normal as is possible. The moodiness Catherine speaks of is not simply the expression of pain – as she says, she is not consciously aware of her pain at all times, although as we discussed this experience, we both spoke of how it is not complete unawareness, but more a ‘background’ sensation, an awareness that can be focused on, but can also be ignored. David described the background sensation of pain thus;

"The best way I can describe it, it's like looking at a landscape, and sort of, using the body image as that landscape, whereas the chronic pain is more something – at the bottom of that lake rather than on that landscape, if that makes sense? It's almost a layer beneath that landscape, and I – it's difficult to sort of, to connect the one to the other – the layer behind that I can't quite perceive properly" (David interview 1).

The experience of chronic pain is not easy to describe when it comes to the background sensation; once we focus on the pain long enough to begin to describe it, it is no longer a background sensation, instead it moves to the foreground of our

awareness. In speaking of pain, we became more aware of it – as though by pointing it out, we were neither of us able to ignore our own pain¹⁵³.

A chronically painful body is an unreliable one; as Charlie observed:

"You can't rely on your body to do what you want it to do any more, your confidence and your sense of control over your own life, it changes" (Charlie, interview 1)

Pain destabilises the self, but chronic pain results not in an unreliable body but a *reliably unreliable* body. While regaining some sense of control may be the aim of pain treatment (such as Julie spoke of¹⁵⁴), pushing patients to consider how to manage their energy and avoid situations that will lead to higher pain, there is also space for coming to terms with a body that is forever unreliable, a phenomenological self that is forever shattered asunder. This takes time; crip time is also the time taken to adjust to a reliably unreliable body.

When it comes to BDSM, the pain that results from play is reliable – it occurs in expected ways, in that it follows after activities that players know will cause pain,

¹⁵³ See p.357.

¹⁵⁴ See p.241.

while chronic pain can spike after activities that are not associated with pain, and even after activities that have been performed without pain on previous occasions. In addition, the pain is likely to last for an expected amount of time – as acute pain, it contains the expectation that it will end. Thus, in playing with pain, participants are further adjusting to their reliably unreliable bodies, by re-establishing the reliability of non-chronic pain and re-confirming the unreliability of chronic pain, its abnormality. BDSM pain in crip time is thus a part of their becoming disabled, their living with chronic pain.¹⁵⁵

Crip time as time to become crip

Living with chronic pain is, like disability, a part of identity;¹⁵⁶ participants all spoke of how living with chronic pain impacted their sense of self. Like disability, chronic pain interacts with other aspects of identity – and the conception of self narrated by participants is not fixed over time. Walden, in exploring the lives of lesbians living with chronic illness, states that a person's experience of illness, of fluctuating levels of pain and fatigue, "is a critical part of the process involved in integrating one's identity as a

¹⁵⁵ See pp. 250, 276, 327.

¹⁵⁶ See p.46 and p.76 for literature sections considering disabled identities.

disabled/chronically ill lesbian into one's identity as an individual" (Walden, 2009, p. 559); the same is no doubt true of people of other genders and/or sexualities, although the details of that process may be different. Edward, one of the older participants,¹⁵⁷ explained that his sexual identity, as well as his erotic and sexual preferences, have changed over time, between and during relationships, and were impacted by how his disability and his age has altered his body. While Edward did not see these changes as the direct result of living with chronic pain or being disabled, he identified points where his experiences were affected by being disabled (such as his use of a wheelchair impacting his access to, and interaction with, social spaces), or by his pain specifically, on a practical and very embodied level (such as how pain affected his willingness to participate in submissive activities) and these experiences were a part of his sense of self.

For other participants, disability and living with chronic pain has impacted their sexuality directly. For some, this impact was not cast as either positive or negative; it simply *was* – this is exemplified by Charlie, who explained that because they¹⁵⁸ acquired their disability as a young adult, they had not had long to establish their sense of sexual self;

¹⁵⁷ See p.229 for profile.

¹⁵⁸ Charlie prefers gender-neutral pronouns; see p.228 for participant profile.

"I was only just becoming sexual before the [impairing event], so I hadn't fully explored my sexuality to any extent, so I can't separate out what my sexuality would have been without living with pain, in many ways. I mean, I didn't do [BDSM] before, except [laughs] the kinky kind of bondage stuff, as a kid, but I didn't seek it out – I suppose other sex was, more conventional non-kinky sex was satisfying, before the injury, so I think a lot of it was connected, uh, but I think I could have equally gone this was in an evolution of my sexuality anyway, so, and I think there must be an aspect of myself that was open to that in the first place, otherwise I wouldn't be doing [BDSM]" (Charlie, interview one).

For Charlie, becoming accustomed to their disability and chronic pain was experienced alongside their exploration of their sexual self, and thus they felt they could not say what they thought their sexuality would have been like had they remained non-disabled. This was not a particularly difficult question for Charlie to answer; they felt secure in their sexuality, and the time they had spent as a disabled person and living with chronic pain meant that they were, if not wholly happy with all aspects of their lives, at least accepting. Acceptance – and happiness – does not happen instantaneously, especially when living in diagnostic limbo can lead to a sense of being wrong, of disbelieving one's own self-knowledge (Wendell, 1996), and when living in a society that insists that disability is abnormal and unwanted. Crip time, therefore,

includes not just time to live on an everyday level – the level of getting dressed or catching a bus – but on a longer timescale, that of a life lived; crip time includes the time needed to establish a positive disabled identity.

Julie, who experienced a great deal of change over the course of the interviews,¹⁵⁹ was less accepting than Charlie and Edward; she was still mourning the loss of her non-disabled and less painful past, as well as the possible futures of that earlier self. Kafer (2013) discusses futurity, in relation to the spectre of a disabled future in terms of non-disabled others looking at disabled children¹⁶⁰; crip time includes embracing a disabled future. However, embracing a disabled future is not always easy, even for disabled people; Julie is – and was – secure in her identity as a disabled woman, but a change in her impairment and the level of her everyday pain forced her to re-examine that identity.

“In chronic pain management, they got to the point of wanky preaching about ‘taking a step back, so the pain is still the same size but the perspective has shifted and so it seems less big and bad’ ... And after coping with a big life, with kink pain, chronic pain, interaction with others, work, fun, etc etc [sic], I’ve now got focussed [sic] on the illness side of things. In a way it never has been before.

¹⁵⁹ See participant profile, p.227.

¹⁶⁰ See p.76.

Some days all I see are my flat walls, and an hour of care from a carer. Others it's the same, but with added in paramedics. There's no space for kink in this life. Let alone kink pain. I'm not depressed, more just going through a period of mourning" (Julie, diary entry).

This change, and the practical restrictions it put on her activities – particularly after discovering that orgasms carried a risk of minor stroke – was an emotional one for Julie, but one she was slowly beginning to adjust to; mourning her possible futures was a part of this, a part of her changing life, and a part of embracing her disabled future. Although Julie was still hoping for a change in her situation;

"I'm clinging onto this being a temporary move rather than a permanent one. It can't get much worse so it has to get better. That's all that I've got left. In a way it's more positive than a few months back when I was mourning lost things, I've now lost so much I have to shift my mindset. Otherwise I'm just a woman in pyjamas in bed with the occasional filthy phonecall. I have to hold onto being more than that." (Julie, interview 2)

This period of adjustment can be a mourning period, even when the person is already disabled, not just because it would be understood as a loss by non-disabled others, but because it is experienced as a loss by those who are adjusting; Julie has been restricted in terms of what she can do compared to her previous capacities, and her

mourning – and frustration – is understandable, because she is no longer able to do something she wants to do. Acknowledging this mourning, giving time and space to become crip – to acknowledge and embrace oneself as disabled, as crip – is a part of crip time; this does not support the positioning of disability as negative, but instead leaves space to acknowledge that an unexpected change to the bodymind needs time to fully become a part of the phenomenological self.

Crip time as time to adjust

In Charlie's words, in acquiring an impairment, or chronic pain:

"There's lots of adjustment. I did lots of adjusting [with the leg injury], now I'm doing a lot more adjusting when the [diagnosis] got bad and now it's not getting better" (Charlie, interview one)

Charlie's experience of pain has changed a great deal since their impairment event – not least because the original injury site is regarded as fully healed – and their more recent experience of increased fatigue and 'everyday' pain levels has led to further 'adjusting,' learning to once again live in a world that is systemically hostile to people living with pain and fatigue.¹⁶¹ Crip time therefore includes the time that individuals

¹⁶¹ See Social Model, p.46.

with acquired impairments – or progressive impairments – need to adjust, to reconstitute their self, within spaces of rehabilitation,¹⁶² but also outside. In turning now to experiences of medicine and rehabilitation practices in this section, I do not intend to support a medical model approach to disability,¹⁶³ or to support the medicalisation of chronic pain,¹⁶⁴ but to acknowledge that medical care is a part – to varying degrees – of the experience of living with chronic pain and disability (Kafer, 2013). Medicine has a huge impact on experiences of chronic pain, especially when some areas of disability explicitly exclude pain as an impairment,¹⁶⁵ and also because treatment of pain is constructed as the responsibility of medicine.

Charlie observed that rehabilitation practices had changed a great deal since they became physically disabled,¹⁶⁶ but although they found increasing attention was paid to ‘whole-person’ and holistic approaches to rehabilitation, it nonetheless took them several years to access particular services, particularly finding medics willing to discuss sexual function, for which they had to go to a different specialist department as the

¹⁶² See pp.59, 118.

¹⁶³ See p.40.

¹⁶⁴ See p.96.

¹⁶⁵ See p.228 for profile; pp.59, 118 on rehabilitation.

¹⁶⁶ Charlie has multiple disabilities – some acquired as an adult, some not; see p.228 for profile.

department who oversaw their care had no remit to consider sex/uality, and felt unprepared to support them. This process of finding willing specialists – the process that Michelle described as *“going through the system”* (Michelle interview one) – takes time to access. The separation of specialists, and the time needed to access specialists, together with the experience of being passed from specialist to specialist for the treatment of seemingly distinct body parts, symptoms, or problems, may be holistic as far as medicine is concerned, but is experienced as a further separating out of the body, a further objectifying of the body (Illich, 1995; Young, 1997) – and a further removal of their expertise and self-knowledge (Wendell, 1996). Furthermore, that access – and the amount of time needed to gain access – is unequal, not just in terms of geographic closeness to a hospital with the necessary specialists, but the willingness (and ability) of doctors to refer the particular individual to those specialists; this can be impacted by race, gender, and age,¹⁶⁷ as well as the specific diagnosis. Rehabilitation time – what Frank (1995) calls the restitution narrative¹⁶⁸ – is not smooth; some of the practices of rehabilitation are painful, as Michelle’s narrative of undergoing ‘corrective’ surgery on her legs in her mid/late teens, that left her with greater pain, as well as changing her bodily shape and movement in ways she was neither accepting of or prepared for. In David’s experience, some rehabilitation or

¹⁶⁷ See p 106.

¹⁶⁸ See pp.59, 118.

pain-management practices are boring (such as physiotherapy, or mindfulness), and there is a great deal of hit-and-miss approaches, trying different practices one after another in the hope of finding one that 'works,' or simply because there is a requirement to try one practice in order to access the next. David found the practices of rehabilitation he was pushed towards had unwanted side effects that he struggled with; he found medication caused him to gain weight, which affected his self-image and self-confidence, and thus reconstituting his self with impairment was made more complicated.

This reconstitution of the self takes time – but it does not begin again every day, with every minor change in pain levels. It is only when there is a significant change – one that requires changes in the practice of living – that the self must be reconstituted again. This is demonstrated by the change in Julie's narrative between her first and second interviews, where she spoke of once again learning to live with her disability when she lost the mobility of a wheelchair and became confined to her bed and her home, with greatly increased pain and fatigue;

"My experience of myself now includes the pain centrally, and most of the time I am controlled by it rather than being able to control it. It dominates more than any dominating person of my choice can have hold over me. My chronic pain is far worse now than ever before, which knocks my confidence." (Julie, interview two)

Julie's experience was very negative, and her narrative seemed initially quite bleak, but she was not the inarticulate non-human¹⁶⁹ that previous theories of pain would have led the listener to believe. In many ways, telling the narrative of her experience was a part of Julie's rebuilding of her self; in speaking of her pain she is able to claim her humanity through performing the role of normal human - one who is able to speak of their pain, to describe it, to play with it, and to have that speaking and play listened to. A big part of Julie's narrative was that of her mourning the loss of her ability to take part in BDSM activities, especially as those activities had played a major role in her previous reconstitution, a few years previously, when she first became disabled. BDSM helped Julie to stop seeing her chronic pain as something to 'overcome' or 'get over,' saying that:

"At first [disability] made me more stubborn. I was going to prove it wrong and be a bigger, better me. Chronic pain was just a challenge to overcome. Since kink? This has allowed me to find a place to move away from the all encompassing pain/disability and just be me. Sure there are times when the chronic pain/disability have to play a part in the kink, I have major limitations, but to work beyond them is liberating. I've explored myself through the kink. Over the last few months I've lost a lot of confidence in my body as it has failed.

¹⁶⁹ See pp.88 and 107.

My image of myself now includes my disability as a major component. I can't be the big and fun me any more, it's got lost in the pain for the time being. Having to hold onto to the hope I'll get "me" back." (Julie, interview 2)

Julie found the space in BDSM to have time to grow accustomed to her new self, to embrace herself even though she was never particularly positive about being disabled, and without BDSM, she was struggling – and was aware she was struggling – to re-adjust. However, this new unreliability was becoming reliably so; Julie was aware of the limitations of her body, and while her final interview was still tinged with loss, her sense of self came through more clearly, she was more confident in her reliably unreliable body.

Crip time as time to manage impairment

Pain management in an unreliable body is not a straightforward matter; the intervals of time between medications can stretch and contort, pain may make sleep impossible, or sleep the only activity possible, and a carefully established routine broken by an unforeseen, unplanned-for event. A day can last forever and also be slept away. Pre-resting to prepare for an event – forcing yourself to do even less in the hope of making more energy available the next day and avoiding pain-inducing activity

can be necessary even though it may prove useless. As Natalie described it, while activity could reliably result in increased fatigue and pain, resting was not so reliable; recovery from a spike in pain could take days, or weeks, or months; kink always resulted in higher pain and fatigue, but was sometimes worth it.

For all the participants, pain levels were not constant; Edward described his pain as intermittent rather than chronic, and the rest all reported that sometimes they experienced more pain, sometimes less. Although there tends to be an assumption that chronic pain is constant, in terms of both intensity and duration, this is not necessarily the case, and while Edward preferred the term intermittent because he had long pain-free periods, his diagnosis is such that his pain could also be understood as chronic, which he acknowledged. Medication helped sometimes, as did a host of other pain management techniques, from yoga to acupuncture; most of the participants used multiple management techniques together, as well as multiple medications, in order to increase the time they spent in less pain, or to live with that pain. For Charlie, kink formed a part of their pain management; they reported that

“in any sort of kink or sex kind of play ... sometimes I've been able to, uh, extend the period between using analgesia because of the impact of the endorphins, and just, whatever” (Charlie, interview one).

For all the participants, kink was not only pleasurable, but produced a temporary relief from pain, in that they felt less pain, the quality of their pain changed, or they were focused elsewhere; I will turn to the control of pain at a later point,¹⁷⁰ but for the moment it is the relationship between time and the participants' experience of their pain that is my focus. Within the context of crip time, then, managing pain requires time – requires time to engage in pain control methods. One of these methods, particularly for those who live with chronic pain and fatigue, is pacing – carefully measuring out time and energy in order to complete tasks without resulting in pain or fatigue flare-ups.

Crip time as pacing

Pace of life, for the purposes of this thesis, is defined as the speed at which everyday tasks and productive work are required to be performed, as well as the time of day (or night) those tasks or work are expected to be done (Kafer, 2013; Kumari Campbell, 2009; Wendell, 1996). As Wendell (1996) observes, the increases in pace of life in

¹⁷⁰ See p.264.

modern neoliberal society¹⁷¹ – longer working hours, faster travel, quicker movement of information – is resulting in increasing numbers of people who are regarded as disabled; the space of crip time is increasing as a result as more and more people are falling short of being ‘on time.’ For Ahmed (2006), in writing of the perception of the failure of objects to adequately enable tasks to be completed, she echoes thinking on disabled people – they are failed objects, in that the body is reduced to an object that fails to enable the tasks of work to be completed; disability is a failure of performance in and on time. The life course of a disabled person is different from an able person, as a result of this failure to perform, and because “certain objects [and ‘choices’] are available to us because of lines that we have already taken: our ‘life courses’ follow a certain sequence, which is also a matter of following a direction or of ‘being directed’ in a certain way (birth, childhood, adolescence, marriage, reproduction, death)” (Ahmed, 2006, p. 21) – here Ahmed is following Halberstam (2005), applying the concept of orientation to time – the queer body’s path through time is orientated differently to the straight body; the crip body’s path through time more closely resembles the queer path.

Thinking through pace of life exposes the compulsory ableness behind constructions as apparently disparate as timekeeping, speed (and method) of movement, and

¹⁷¹ See p.70.

development of various 'skills' in childhood; crip time runs alongside Lochlann Jain's (2013) *prognosis time*, the time of life at which diseases appear, the time of terminal illness, between diagnosis and death; the sick body exists in prognosis time, and "The prognosis epitomizes the haunting character of death ... In one swift motion, the cancer prognosis detonates time, which scatters like so many glass shards" (Jain, 2013, p. 28). Although none of the participants had been given terminal (or life-limiting) diagnoses, both Edward and Julie lived with progressive conditions, and thus live in prognosis time as well as crip time; they have diagnoses that come complete with timescales, bodily selves forever in anticipation of 'worsening' impairment, together with the anticipation of a future remaking of the self, of re-adjusting to another self.

Debility¹⁷² presents both danger and opportunity to think through the notion of pacing, and the impact of pace of life on bodies positioned as both disabled and not. Opportunity, because the notion of debility, as a way of thinking about how the pace of life impacts on bodies and lived experience, arguably "[affords] greater recognition of geo-social forces and circuits" (Wearing *et al.*, 2015, p. 2), but also a danger, as "concepts such as impairment and debility do not indicate new modes of egalitarianism but, rather, operate as a superficial rebranding of medicalised paradigms" (Inckle, 2015, p. 43). Taking the approach that both views have a measure

¹⁷² See p.71.

of value, pacing can be read as a double-edged sword: it gives space to acknowledge that a normal (and ever-increasing) pace of life is impossible to achieve, and instead further debilitates disabled bodies, wearing them down through continual demands to keep up – but pacing can also be read *as* that same demand, as a requirement to perform. Pacing is a performance of a slowed pace of life, but, also a performance of refusal to wholly reject the normal pace of life – instead it is a performance of striving for normal through tightly controlling the body.

When it comes to living with chronic pain, which is so often accompanied by fatigue, a great deal of emphasis is placed on ‘pacing’ yourself as a form of pain management – especially in rehabilitation settings – and the need to ‘manage’ time and lower-pain days so as not to provoke periods of increased pain or fatigue. While pacing is useful, it is also frustrating, irritating, and runs counter to the ideal of achievement; as Catherine put it:

"Oh yes, pacing. I'm relatively good at pacing, practically speaking. Emotionally it kills me - especially while I've got a lot to do, like right now. If I have a list of tasks and have to go to bed, I get REALLY angry with myself. Like 'what are you even for?' angry. But practically speaking I can do it, and I know I have to"

(Catherine, interview 2)

However, pacing also opens up the individual to victim-blaming discourses, where a failure to properly perform pacing is a failure of proper self-care, a failure to use the full “range of market commodities that hold out the promise of therapeutic interventions into the relative failures of physical, cognitive and affective embodiment” (Shildrick, 2015, p. 11) offered by neoliberal society. Those who practice pacing, who attempt to manage pain by managing their time, are caught between a rock and a hard place; the demands of keeping up with the pace of life require pacing, but those demands are such that they will never be properly met, as neoliberalism keeps bodies as always debilitated in order to sustain profit and markets (Mitchell and Snyder, 2015; Shildrick, 2015). At the same time, if pacing is not seen to be properly performed – or even if it is – and it (inevitably) fails to adequately prevent pain or fatigue, it is the *individual* that is marked as a failure, and the pace of life is not questioned. Crip pacing, therefore, is not just about self-management to optimise production, but self-management to optimise *joy*, to take care of oneself and pleasure in that care; crip pacing as a form of politicised self-care (Ahmed, 2014).

As Siebers (2008) points out, passing as normal is exhausting; for participants who live with fatigue or limited as well as chronic pain, passing as normal can only be sustained for so long, if at all. David finds his pain and fatigue impacts every aspect of his life, and when it comes to his BDSM play, he knows that playing for longer periods of time, or maintaining certain positions, or movements, is difficult, and this requires him to

explain to and negotiate with his partners – such as needing to change position, or to only use certain equipment. It is this performance of disability – of making pain and fatigue visible – that is undesirable, that desexualises him, and thus is risky for David, opening him up to abjection and being repositioned as less-than-able, and thus less-than-human.

Julie, on the other hand, finds a certain freedom in living with fatigue and pain, saying:

"I only have limited energy and stuff with the pain, so I have to – I get the choice. It's quite liberating in some circumstances, I find, cos I now have to choose what I do and don't do, I can't just do everything, uh, because I've got these limiting pains, so I – I do appreciate all those choices I make." (Julie, interview one)

In being forced to make choices – sometimes difficult choices, as Natalie's narrative of missing such socially-significant events as funerals and weddings showed – due to a mismatch between the pace of life and the restrictions of an ill and painful body, Julie and Natalie are made disabled, pushed to live as abnormal. However their sense of liberation shows that matching the pace of life demanded by ableist social structures is not necessarily rewarding in itself; there is no inherent joy in being normal, while being abnormal can be (or can be made to be) freeing and joyous. This joy in rejecting a normative pace of life (even if the rejection is the consequence of a loss of capacity)

demonstrates the joy that can be found in living *crip*, in *crip* ways of moving through time.

Natalie spoke of her need to weigh the energy costs of each activity – asking herself if she has the energy to do the activity in the first place, and if the resulting pain and fatigue will be worth both the loss of energy and the outcome of the activity. While this may seem like a simple cost-benefit analysis – the risks of an action against the risks of not doing it – there is both great pressure to *do*, to meet the pace of life and activity level demanded by normative society; it is not acceptable to only do some of the task (some of the shopping, part of the wedding), or to admit that the reason for not doing any of the activity is that while you may be able to *right* that moment, you have decided it will not be worth the pain or the fatigue that will result, even if the resulting fatigue will impact your ability to complete other activities. This is because the admission of pain and fatigue is a reminder that they are abnormal, forcing the listener to face not just the pain of the speaker, but also the possibility of their own pain. Speaking of pain and fatigue also forces the person in pain to confront their pain again – to acknowledge that pain is a part of their lives, that they live an abnormal life; it is this discomfort that Julie showed when admitting she rarely told others she lives with chronic pain.

For Charlie, who has lived with chronic pain and fatigue for many years, but has more recently experienced an increase in fatigue, the endurance aspect of their BDSM play particularly appealed to them, as a counter to experiences and sensations of hardship. I also interpreted Charlie's narrative of the appeal of 'enduring' through BDSM as to include countering the sensation of fatigue, a way of speaking back to fatigue. Charlie, however, felt it was more about experiences of trauma and hardship than fatigue – feeling that instead fatigue limits their capability to endure – and was only about fatigue on a very limited level. I wish to draw attention to the differences in understanding here¹⁷³ as it highlights how multiple readings can be found in the same narrative; it is perhaps my own experience of fatigue that has affected my reading of Charlie's narrative, and assigning greater importance to fatigue than they have done. I wish to acknowledge this difference, but also concede to Charlie – and thus emphasise that the endurance aspects of some forms of BDSM play (flogging, but also bondage, in particular) played a role in Charlie's integration of their experience of hardship and trauma into their self.

Running parallel to Charlie's narrative of why they consciously choose to engage in play, Natalie's narrative showed that it is also difficult to acknowledge when she has decided that a particular activity (not just sex) is worth the pain and fatigue – and

¹⁷³ As well as in the more general account of the methodology, see section beginning p.346.

particularly so when the activity could be deemed 'frivolous' or even selfish by an observer, such as when the activity serves no function beyond the pleasure of Natalie (and her husband). For Natalie, BDSM served as a reward, as a celebration of periods when she felt herself capable of enduring, of being strong – as well as something to look forward to in the times when she and her husband both felt unable to do what they wanted to do; she explained that:

"When we're both in poor physical shape and can't do much, we talk about all the things we'll do when we're better" (Natalie, interview 1).

David also saw that time when he was not capable of engaging in BDSM play as a potentially useful;

"At the same time, a case of roll with it, figure what is possible; sort of make use of the time to connect in other ways. Talk. Bounce ideas backwards and forwards. Just making time can be a... it's not wasted time" (David, interview two).

This 'useful' downtime, a time to talk and reassess – however playfully – is a part of crip time, a part of its ebbing and flowing, and can be fought against or it can be gone with; it can be accepted, or rejected. Pacing as an act of self-care can require going with the flow, but can also take the form of fighting back, refusing to go with the flow, even though this makes the body less reliable, increases the chances of a flare.

Crip time as time to think and do slowly

A flare in chronic pain can often be accompanied by other changes in the capacities of the bodymind. When my own pain flares, I am more tired, my balance and sense of bodily orientation in space is altered – I fall more easily, struggle to judge distances or hold objects – and my cognitive abilities are limited, I struggle to communicate, or to understand. Cognition may not, at first, seem dependent on time, but there is space to consider how people with cognitive impairments and people with learning disabilities are often described as ‘slow’ – slow readers, slow to meet developmental targets, slow to understand. As Chen describes it, writing through the concept of crip cognition, “maybe we can talk about an expected temporal trajectory, not consistent throughout but—like sexual development narratives—having its own proper spurts and ebbs, a mapped journey of cognitive elaboration (known to cognitive scientists and paediatricians as development), such that a cognitive identity can be felt and affirmed in a way that produces the effect of a ‘cis’ [cognitive ability]” (Chen, 2014, p. 178) – and those of us with unexpected trajectories and abnormal cognitive abilities are something queer, something crip. This acknowledgement of non-normative cognitive identities – as distinct from both cognitive ‘normality’ and the neuroatypicality identified by autistic individuals (which itself may be considered to

overlap with crip cognition) is reliant on the understanding that “An information-handling reading of cognition, rather than being a remote disciplinary feature proper only to cognitive science, is integral to the prevailing mechanisms for the contemporary production of knowledge” (Chen, 2014, p. 178); ableism is expressed in a preference for normative *thinking* as well as normative ways of doing and being.

For the participants, pain and fatigue was sometimes accompanied by ‘brain fog,’ a state of thinking slowly, of a fogged-up brain, of a loss of cognitive faculties akin to having one’s brain replaced by marshmallows and where following a thought is like wading through treacle. For Natalie, the cognitive symptoms of impairment “killed [her sexuality] dead” (Natalie, interview 2); she reported feeling very few, if any, sexual feelings, experienced no sexual desire – and as a result did not feel any particular sexual identity. For other participants, brain fog impacted their sense of self, not as pain did – brain fog being temporary, while pain was a constant (if fluctuating) experience – with temporary loss of faculties leading to their frustration with themselves, and awareness that they frustrated others with their inability to communicate easily or grasp basic facts. For Catherine, this was in addition to the more everyday effects of her neuro-atypical cognition.

Conclusions

This chapter has explored how the participants' narratives told a story of crip time, as well as expanded the notion of crip time itself by demonstrating the relationship between chronic pain and time. To begin with, crip time includes time for diagnosis and to access care; it is a form of limbo, between becoming disabled and being recognised as such by gatekeepers – and thus a time of instability.

Parallel to this runs crip time as time to *become* crip, to integrate chronic pain into one's identity, one's sense of self – to become a person *living with* chronic pain, rather than a person *in* chronic pain. This involves a period of mourning, for the loss of possible futures and past self, and time for an unexpected change in the capacities of the bodymind to become a part of the phenomenological self.

Adjusting to the new capacities of the bodymind is a part of learning how – and when – to pace; the third part of this chapter's contribution to the notion of crip time is time to live at a new pace, and time to practice pacing (and lack of pacing) as self care, deciding to push oneself into exertion, deciding the activity is worth the higher pain – or deciding it is not worth one's energy and capacities.

Finally, this chapter explored the notion of crip time as time to think slowly, of crip time with brain fog – and the impact of chronic pain, particularly flares of higher pain, on cognitive function, and how that impacts the self.

The link between crip time and BDSM ran through several parts of this chapter; there is no single point at which BDSM becomes crip – or at which the time spent in BDSM activities can be defined tidily as crip time. For some of the participants, the time spent in BDSM was time spent to engage positively with their crip self in ways that are loving, that include desiring/being desirable – that present their bodyminds and not just desiring, but as desirable, whether publically (and playing in view of others) and/or within a private space or intimate relationship. It is through this presentation of the disabled bodymind as desirable that engaging in BDSM makes this time a part of crip time – a part of time to develop a positive view of the disabled bodymind, a part of becoming crip. BDSM also became a part of participants' experience of crip time as a part of being reliable – as a part of establishing their sense of control; while the demand for self-control is – as the next chapter will demonstrate – a very normative one, the ways in which control are sought are very crip. Thus a specific time to engage with the bodymind – to focus on the bodymind and its capacities – is a form of crip time.

Pacing, like BDSM activities, involves a measure of control, particularly controlling activities in order to prevent pain. This is tied up in the pace of life under neoliberal regimes – and how disabled bodies are often further debilitated, if not disabled, by the demands of a fast life – as well as increasing demand for self-control and self-regulation. It is to control that I turn now.

Chapter Six: Control

Control, in this thesis, has several meanings. Firstly, it means control of the self, self-control, as containment of the body, control of movement and of emotions. Secondly, it includes control of pain – whether by making pain, altering sensation, or controlling emotional reaction to the sensation of pain. Control of pain is a form of self control, in that it is controlling what affects the bodymind, and how the bodymind responds.

This chapter explores the theme of control in narratives of pain experiences, particularly in terms of emotional responses to chronic pain, and talking about pain – as discussed in the literature review at the start of chapter two.¹⁷⁴ The uses of BDSM overlapped with control of pain – in a more obvious way than BDSM did with crip time, although there is overlap with how time interacts with control.

Self control plays an important role in neoliberal regimes; individuals are expected to have control over their bodyminds and to therefore take responsibility for their capacities, for their abilities – and a loss of capacity is due to a failure to properly

¹⁷⁴ See section starting on p.88.

control the self, whether that is by failing to properly perform healthy behaviour, or by failing to properly engage with rehabilitation practices. Disability, therefore, is failure to properly control the self.

Theorising understandings of control enables further links to be drawn between social expectations of a normal bodymind – in terms of comportment, containment, and capacities – and crip uses and contestations of control. The uses of control by participants is an important consideration – control is not easily divided into normal and abnormal, into control and lack thereof, and nor should it be; as participants showed, they contested demands for control even as they sought out control – and sought spaces to be uncontrolled through other forms of control. Their contestatory and complicated narratives of control often conflicted, but nonetheless control played an important part in participants’ narratives of chronic pain, particularly in terms of controlling pain – both in an attempt to perform proper humanity, but also in an attempt to re-establish their phenomenological self in the face of an unreliable bodymind. I want to open with a quote from Julie, who explained how she felt about controlling her chronic pain:

"Controlling pain is important. Whether that be resting to decrease some pain, using painkillers if they work, moving position at the simplest level. Kink is

taking this to its natural conclusion by making pain to control" (Julie, interview 2).

Choosing terminology in this section was not easy; there was no single phrase that jumped out at me. Participants spoke of 'managing' pain, of 'coping with' pain, fatigue or frustration, and spoke of feeling as though pain 'controlled' their lives. I went with control because it felt closest to what I heard and felt; the need to make conscious decisions about how to interact with their pain, the need to feel connected to their bodymind, the need to perform in expected ways in order to access care. There is possibly another word that would encapsulate all this better, but neither my participants or I could find one.

Sex and Control

The control of emotions is a part of self-control, whether those emotions are understood as positive or negative by observers; controlling emotional responses to experiences of pain, disability, and chronic illness is a necessary part of performing proper bodymindedness, particularly for disabled people and people living with chronic pain. Controlling emotion does not mean expressing little emotion, but

performing *proper* emotion, or expressing emotion in appropriate ways. This is exemplified by how children learn to react appropriately to acute pain incidents – for example, when a small child, still learning to walk, falls in the process of play and scrapes a knee, their tears and vocal cries are accepted as a ‘normal’ reaction by other small children and adults, although their parent may seek to quieten their response with cuddles and fussing over their injury. However, when an older child falls during play, they may well try to hold back tears, to ‘get over it’ quickly and continue their game, not seeking out a parent’s attention; a child who fails to contain their reaction may be mocked by their peers as a ‘big baby,’ and if that child is a boy, he may be told to ‘man up,’ or another phrase implying that expressions of hurt are feminising as well as improper. To say that the smaller child feels pain more is to do an injustice to the older; the older child may well have felt like bawling and demanding that somebody kiss their knee better, but they have learnt that it is not appropriate behaviour. Proper bodymindedness requires proper emotional control.

Chronic pain, and the emotional response to living with it, is an emotional minefield. Catherine spoke of expressing her pain as irritability, anger, and depression – experiencing depression in particular is common among those living with chronic pain (Nielsen and Fernandez, 2010; Thomas and Johnson, 2000), and those living with

chronic pain are frequently prescribed antidepressants along with analgesics.¹⁷⁵

However, there are proper and improper spaces and times in which the emotions of pain can be expressed, as well as proper audiences; expressing pain and weakness is a private act. For the participants, finding times and spaces to express emotional responses to pain – as well as a receptive audience – was one of the pleasures of BDSM, which provided a space for engaging with bodies and emotions. This is not to say that BDSM is free of control – or *out of control* – but that the rules of behaviour in play make space for emotions, for screaming and crying and seeking comforting touch. The expression of emotion is encouraged, even required.

As chronic pain is expected to be - and very frequently is – emotionally negative, as living with chronic pain can lead to a negative perception of the bodily self – especially a body that is unreliable,¹⁷⁶ and so frequently the object of others' abjection.¹⁷⁷ This only becomes increased when the person living with chronic pain must restrict the expression of their emotional response to their chronic pain, limiting what they express, where they express those feelings, and who is present when they do. Many

¹⁷⁵ It should be noted that some drugs usually prescribed as antidepressants also act as muscle relaxers, which can reduce pain levels.

¹⁷⁶ See p.235.

¹⁷⁷ See pp.65, 299.

participants spoke of feeling pressured to remain silent¹⁷⁸ and limit how much, and to who, they expressed emotional responses to their chronic pain, and this did sometimes include when interacting with play partners – as focusing too much on their chronic pain would make them less attractive as a play partner. Charlie explained that they kept explanations of chronic pain to a minimum, focusing on the practical aspects – such as where they could not be flogged – unless they were playing with a friend, or someone who also lived with chronic pain. This practical, quantitative, emotionless evaluation of pain was something participants mentioned performing for medics and care providers, particularly in cases where they felt an emotional response would not help them access medication or care – for fear of being labelled drug-seeking, hysterical, or exaggerating. This tactical performance of pain, while sometimes useful, cut both ways; Charlie and Catherine both felt that being unemotional about their pain meant listeners could be less sympathetic – and less inclined to provide medication – but that being perceived as too emotional meant that they were less likely to be believed. Expressing emotional responses to pain was a minefield for all the participants, and one that they all negotiated carefully.

However, in using pain within their play, participants were able to engage emotionally with their pain, and with their bodily selves, in a controlled space, and in ways in

¹⁷⁸ See p.88.

which they were in control, rather than relying on the judgement of medics or caregivers, as Julie explained;

"It's about controlling my body, or allowing someone else to control it, in certain ways" (Julie, interview 1).

The act of receiving pain was a way to connect with the somatic sensation of pain, and express emotional responses, but an activity they could call a stop to - as well as an experience of pain they know will end. Julie explained that when it came to chronic pain,

"[she deals] with not dealing with it.... And so then the, um, the kind of kink pain is kind of dealing with it and kind of exploring through that ... so it's not shutting it all out as far as I can, it's actually experiencing it" (Julie, interview 1).

This control of the experience of pain, and the space to be uncontrolled in their response to pain, can be read as the opposite to living with chronic pain – an experience that they did not choose to have, and that they cannot put an end to, but nonetheless are required to be controlled in their response to – and thus is a space to speak back to the pain.¹⁷⁹ For Natalie, BDSM play turns her menacing chronic pain into something else, something she is able to experience as painful but also positive, and she sees this as a conscious subverting of her experience of chronic pain through

¹⁷⁹ See p.315.

BDSM play; in this way sex and play is, for her, an act of reclaiming the self, and of creating a space of emotional response. Julie found that BDSM play provided her with a space to re-engage positively with her bodily self;

“[BDSM]has allowed [her] to find a place to move away from the all encompassing pain/disability and just be [herself]” (Julie, interview two).

This ‘being herself’ comes complete with expression of emotion – a space where Julie is not pressured to be pain-free, or to perform disability. Julie did not start practicing BDSM until after she first came to live with chronic pain, and her interest in play pain and submission developed alongside her new identity as a person living with chronic pain. She feels that, through BDSM, she is

“starting to understand [her] body beyond the pain, beyond the chronic pain ... beyond the pain even if it's been induced even in a kink-type setting” (Julie, interview two).

This understanding of the self, of the bodymind can only come with expression of emotion, with space to fully feel, and BDSM gives Julie a positive experience of pain, and of her body, even with chronic pain, which she had experienced, and continues to experience, as overwhelmingly negative.

BDSM and sex together, for Natalie, are

"the opposite to illness – the latter makes my body feel ugly, useless and thoroughly dysfunctional but sex (these days) makes me feel beautiful, physically stronger and useful both to myself and [my partner]" (Natalie, interview 1).

As a space to engage positively with her body, in a way that works *with*, rather than against, its limitations and capabilities, sex and BDSM gives her a great deal of self-confidence. This was a theme that ran through several participants' interviews, whereby BDSM practices help to construct a space in which the limitations and capabilities of the body can be explored;

"The focusing pain calms me, the sensations aren't as deep and pervasive as in chronic pain, the pain is specific. I can appreciate it changing sensations, the pain peaking and troughing. I react in many ways to kink pain, it invigorates me, it turns me on, it allows me to breathe deep full happy breaths. My body doesn't cope very well to non-kink, non-chronic pain, it tends to exaggerate the sensations, making a papercut seem highly painful. It goes into shut down mode quite quickly in these situations" (Julie, interview 2).

For Rita, Charlie and David, the control over their pain is framed in a more 'typically' BDSM manner – and in terms of their BDSM play, rather than their chronic pain – and is focused around their wish for a sense of endurance, and of having pushed their limits. Rita explained;

"I mean, one of the things I get most out of play, of kink play of all kinds, when I'm subbing is a feeling of achievement. Kind of a feeling I've done things well, which both my partners are very good about reinforcing at every opportunity. And especially when I spend quite a lot of my time being bed-ridden and a lot of my time being ... inconvenienced by pain and fatigue that... you know, to be able to go, well, I took that... you know, I took that caning, and it was actually hell, but I feel so good about having been able to do it. It is a really, really powerful thing" (Rita, interview 1).

This narrative echoes Newmahr's identification of a discourse of 'investment' pain in BDSM, in which submissive SM players, typically masculine individuals, explained their use of pain as one of enjoying the sense of endurance (Newmahr, 2011). For Charlie and David, the sense of achievement which they both feel on having incurred consensual pain is one in which they are reminded of their bodily ability and strength, of a sense of mind over matter, which is denied to them through living with chronic pain.

All the participants placed importance on their ability to control their pain, and in ways they chose;

"Controlling pain is important. Whether that be resting to decrease some pain, using painkillers if they work, moving position at the simplest level. Kink is

taking this to its natural conclusion by making pain to control." (Julie, interview 2).

BDSM provided some of the participants with a way to control their chronic pain, through creating increased pain, which will be stopped at any point in the near future, and that they can both plan for and control - through discussion with their play partner, and through calling a stop to the scene. Catherine explained that exploring what she gets pleasure from, or not, is important;

"I can try something, rather than having it sort of imposed on me that this is the situation. And I can find out if it's a type of pain that I like or not. So some things are not a sort of pain I enjoy" (Catherine, interview one).

In Julie's words;

"I think, um, I like it because it's being in control of the pain. Or there's a level of, yeah, I'm in control rather than my body being in control. Even though my body then reacts to the pain in certain ways. But it's that I'm deciding to have pain, rather than it deciding to have me, type stuff" (Julie, interview 1).

Julie is using BDSM to create pain which she can control, but also in a form she enjoys; Julie enjoys the performance of submission, the performance of painful play, and this enjoyment makes the control of pain pleasurable for her, even though the experience of pain is not. In this way, her BDSM play creates a space for re-engaging with the body and somatic sensation in ways that are both pleasurable and painful. The control

of pain and bodies practiced by the participants seeks not to control the pain directly (as it would be through pain medication or pain reduction techniques) but instead to control what can be controlled; namely their bodies responses to pleasure and new, temporary, pain.

"Kink pain is about proving otherwise. It's about laying yourself vulnerable, and opening yourself up to your own strength and the strength of others. You are giving something away, but similarly getting so much back. And testing your own resolve. Because in any kink pain situation, you can stop it if it gets too much - even if you then regret it moments later. Chronic pain is nothing of the sort. It tests you. It can, however much you rise above it to get through it, bring you crashing down. And you can't say a safeword and step away from it. It makes you fragile, to some extent" (Julie, diary entry).

For Julie, the key difference between kink pain and chronic pain – strength versus fragility – is down to control; chronic pain makes her fragile, because she cannot control it. The experience of disability can often be one of powerlessness, and vulnerability – even if powerlessness and vulnerability are only imposed by others, rather than a condition of bodily capabilities and limitations – and in constructing a space where one's vulnerability can be tested, however artificially, BDSM play is a space where Julie is *not* vulnerable or fragile, but strong and desirable. As Natalie

explained in her second interview, kinky sex is therapeutic for her – it is a space of recovery, and positive bodily experience.

Pain and Control

If we take the understanding of pain as an attack on the phenomenological self¹⁸⁰ (Langdridge, 2007a; Scarry, 1985), and that therefore the experience of pain requires a remake of the world and of the self, we then need to consider how the world and the self is remade within chronic pain. If we take the assumption that chronic pain works on the phenomenological self like acute pain, along normative lines, it requires the person living with chronic pain to have the world and the self constantly broken and remade. I would argue, however, based on the narratives of the participants, that chronic pain is experienced differently to acute pain – it is not experienced as externally-caused, imposed from outside the self, and once pain is established as chronic, it has no expectation of stopping in the near future; furthermore, the pain must be lived with. Chronic pain does not require constant remaking of the world and of the self because it becomes the new state of being; one becomes a person who lives with pain rather than a person, or body in pain. The normative reading of pain

¹⁸⁰ See p.88

does not fully grasp this, pain is not supposed to be normal because understandings of pain are that it is acute, that it will pass in time.

For my participants, it was impossible to maintain a state of inarticulate, dishuman distress for very long, although periods of high pain are often experienced as exactly that – periods when pain becomes all that can be experienced;

"You might have to close off because of pain, because that's all you can deal with, but at times where it's sort of moderate to background, you can engage with it in different ways, it's not shutting you down in the same way. There's times when it's just too extreme, you just have to shut down, take yourself away, and those are the times you don't do anything with anybody" (Charlie, interview 2).

But afterwards, once the period of high pain has ceased – even when pain is still experienced – they desired to find the self once more, to counteract pain and to re-establish their human selves – more simply, to actively live. When chronic pain changes in the long-term (rather than day-to-day fluctuations), it is not quite a new experience of pain, as the person is already living with chronic pain; they have already experienced what it is to remake the self – as demonstrated by Charlie's recent, and

Julie's ongoing, changes in pain types and levels. Julie's impairment is progressive¹⁸¹ – it is expected to get worse in time - and as she explains,

"Loss of control is a big part of disability when it is a progressive condition like mine. I've slowly had to give up things that I thought were important or vital to life (even if I now think of them as solely distant memories and nothing particularly important). I try to "just accept" as stressing about what I'm not doing doesn't help me feel any better in this moment in time" (Julie, interview 2).

Catherine and Julie explained that they found that, over time, their chronic pain has not lessened, but it draws less of their focus; they are able to continue on (as indeed they must), and the periods of high pain became less destructive to their phenomenological self. Living with chronic pain meant that they had to continue to act in a way that is 'the new normal,' partly to avoid becoming an object of horror, disgust, and abjection (Kumari Campbell, 2009; Miller, 1997; Shildrick, 2009; Tyler, 2013), but primarily to balance being in pain with functioning. They had to find a way to experience the sensations of life and our sensations of self even as pain reduced their experience of the world, to integrate pain into their lives so that they are able to continue.

¹⁸¹ See p.252.

Despite this need to remake the self with pain, balancing pain in functioning is not wholly sustainable; pain must be given into. BDSM provides a space for giving in to pain;¹⁸²

"That prickly pain of a slapped face. The deep ache of the next day, pulled muscles and all. That bruise that lingers for what seems like weeks. That can keep me going through the difficulties of the chronic pain. Chronic pain limits me, however much I try to believe otherwise, whereas kink pain frees me. Centres me in the moment, or the experience, or the continuing enduring effects thereof. That's why it matters" (Julie, diary entry).

Julie's loss of control over her chronic pain came about because of a change in her disability,¹⁸³ and thus as a result of the loss of bodily capacity and capability she had to stop the majority – and eventually all – of her BDSM play, which has meant that she has lost both an important source of pleasure, but also a large part of her phenomenological self;

"Chronic pain was just a challenge to overcome. Since kink? This has allowed me to find a place to move away from the all encompassing pain/disability and

¹⁸² See p.270 on controlling emotions, and p.327 on making pain.

¹⁸³ Which is progressive; see p.252.

just be me. Sure there are times when the chronic pain/disability have to play a part in the kink, I have major limitations, but to work beyond them is liberating. I've explored myself through the kink. Over the last few months I've lost a lot of confidence in my body as it has failed. My image of myself now includes my disability as a major component. I can't be the big and fun me any more, it's got lost in the pain for the time being. Having to hold onto to the hope I'll get "me" back." (Julie, interview two)

This change to the lifeworld¹⁸⁴ has led to Julie living in a period of mourning;¹⁸⁵ she mourns the very real loss of her bodily capacity, but also the loss of her pain control method, and the loss of her lived experience, particularly as her preferred BDSM play space was a club – and therefore she has lost emotional and erotic relationships now the space is no longer accessible to her. As Julie points out, she no longer feels like herself; the change in her pain and fatigue levels has affected her phenomenological self – but she has not just been destroyed; she is instead going through a period of re-adjusting to her new self.

¹⁸⁴ See p.86.

¹⁸⁵ See p.241.

Charlie's experience of a change in pain and fatigue contrasted with Julie's, not because they are not experiencing a change in their phenomenological self, but because they are a little further on in their journey; the change is not so immediate, and there was less of a sense of mourning in how Charlie discussed the change in their lifeworld, even as they acknowledged the difficulty in adjusting;

"Like I would have used it more in the past, it's been harder since the [diagnosis] and the more pain and just, my body's feeling less robust " (Charlie, interview 1).

This difference may not be due just to time, however – it may be because Charlie's change in chronic pain is due to a *new* disability alongside the worsening of their original; it may be because Julie used BDSM as a primary method of pain control, while Charlie used it more for pleasure and re-establishing bodily ownership. Charlie felt that there was a tension between their bodily response to pain in BDSM, and their cognitive function, explaining;

"I noticed that I used to deal with my pain a lot through my mind, and I suppose now because the fatigue affects my cognitive function a bit, I don't have those mental resources to deal with the pain either." (Charlie, interview 2)

Charlie's feeling that they lack the cognitive function to deal with their chronic pain - particularly the energy to focus their thoughts on anything other than pain, and thus

resist the breakdown of self – is a feeling of a loss of control over their chronic pain, and a loss of control over the self.

It is this notion of control, control of the body and control of pain that has been particularly notable in my interviews, with participants seeking to find ways to not just regain a sense of control, but to regain their sense of self through exercising control over how they live with their pain. The world is at once shattered and held together through control, and finding a way to regain that sense of control is important to the re-establishment of the phenomenological self when living with chronic pain. BDSM, for most of the participants, was a key part of regaining that sense of control - but it also served other purposes. For Charlie, piercing and body modification are a part of BDSM,¹⁸⁶ and they practiced piercing and body modification as a part of reclaiming control over their body, particularly after their disabling accident;

"And I know that [piercing and body modification] was about, sort of voluntary seeking pain, it was shortly after having been injured and having been living with disability and chronic pain, so it was all about my body in voluntary, more positive kind of ways, um, I supposed maiming it in voluntary ways and experiencing the pain in sort of, a controlled situation" (Charlie, interview 1).

¹⁸⁶ Body modification and piercing is not always considered a part of BDSM; in Charlie's life the two activities are connected.

These practices are painful – involving a deliberate breaking of skin, although they are not intended to cause long-term *harm* – and for Charlie, the practices were a pleasurable and positive re-establishment of selfhood, and of their “ownership” of their body. This ownership is also expressed by participants in terms of self-awareness, of knowing their bodily capacities and limits, and how pain affects those capacities;

"sometimes it's okay to just be with it, but also learning to listen to your body so that you can... so that you can manage it more. ... But also understanding what your body's saying as well, because there is that balance, that I thought, if I just... If I just went into my fatigue, I wouldn't get off the sofa ever, or something. You know? But you have to then figure out what are the times when you can try and work with... you know, continue through it, or when you do just have to sit with it. ... Because you could just sit with it all the time and do nothing, but there's also the danger of going the other way and trying to push through it when you're not going to be able to get through it. It's just going to make it worse. So it's about staying active in a way that is sustainable, or is safe, that is not going to have the same... But you can't always predict it"
(Charlie, interview 2).

This awareness is a part of control, in that it is necessary to know when control is possible – and when pushing oneself to the limit of one's capacity is possible, or necessary. Charlie, like other participants, used their self-awareness to decide when and how to play, but as Julie explained, self-awareness is in itself painful, because it requires being aware of pain; there is a tension for all participants between enough self-awareness to engage with the world and the self, and experiencing pain so much that it becomes overwhelming. Thus, control of awareness becomes necessary, and for Julie, this is a conscious process;

"I can't now remember what it's like not to have [chronic pain] there, um ... and as such I cope by kind of, by not being in tune with my body at all, um, and basically by living in my head ... which is fine until I break a leg or something and I don't notice [laughs] ... - so I don't, I kind of stop taking any signals from my body, because it's just, yeah, if all I'm getting back is 'that hurts, everything hurts' type stuff, I just kind of have to go through it all..., I'm often completely unaware of when my body is massively complaining because – because I'm not listening to it" (Julie, interview 1).

This awareness – this refusal to let the phenomenological self shatter under pain – is not necessarily conscious, or deliberate; it is a part of living with chronic pain.

Self Control and Containment

Charlie identified the notion of control as an important part of living with chronic pain – but particularly the discourse of *self* control, that to perform proper bodily humanness, a person must perform proper control;

Charlie: *"Well, it's about control again, isn't it? This idea of we're supposed to be in control.... Something you can't control and it just sort of spills out."*

Interviewer: *"Yeah. So a space for it to spill out is sometimes..."*

Charlie: *"Useful... and welcome and wanted. Sought out"* (Charlie, interview 2).

Charlie went on to explain that pain is sometimes reacted to as though it were a bodily fluid – one that should be properly contained within the body, and certainly not allowed to leak out in the view of others;

"[Pain] doesn't necessarily impact on people in the sense that you're not going to piss on somebody's seat with your pain, but... so it's slightly different, but... So in some ways, there's even less scope for it to spill out, because people don't see it when it does." (Charlie, interview 2)

This need for bodily containment is echoed in discourses of 'leaky' bodies,¹⁸⁷ particularly bodies which menstruate, the incontinence of very young or very old bodies, and the incontinence of disabled bodies (Liddiard and Slater, in press). Failure

¹⁸⁷ See p.302.

to contain leaks – failure to keep uncontrollable leaks private – is incompatible with proper bodymindedness, and a failure of proper self control. Expressing pain works as a leak because it is horrifying, abject,¹⁸⁸ and could be particularly significant for Charlie, as a trans person, because leaking is feminizing (and thus also horrifying to the observer, as a signifier of leaking femininity). Expressions of pain are reacted to in the same way as leaks of physical fluids, as though observing/acknowledging the expression of pain will make that pain contagious – will cause the observer to feel that pain.

BDSM is both a space to forgo control,¹⁸⁹ and to express pain, but also served as a space in which to relieve the social pressure to contain responses to pain. This echoes discourses of submission as relief from high-stress, high-responsibility employment (Newmahr, 2011; Weiss, 2011) – the proverbial submissive man as successful businessman by day, kinky submissive by night – but for the participants, this discourse is used to create space for submission and receiving pain as relief from chronic pain and self-control. Julie exemplified this, explaining

"I'm known for being efficient, I think I control as much of life as I can (and others if given half the chance, in my professional life that is). Part of my kink is

¹⁸⁸ See p.65 and p.65.

¹⁸⁹ See p.270.

submission, giving that control to someone else in some ways, and letting them control my pain levels. That giving over of control is really important to me."

(Julie, interview 2).

Julie used BDSM to create a space where she felt it was safe to engage with her body – where she could allow herself to fully experience her chronic pain, which she otherwise pushed to the back of her mind. In addition, she felt that BDSM was a positive experience of pain, compared to chronic pain. She explained that when she experiences her highest pain, she finds it overwhelming;

"I long for release, to finally feel myself pass out from the pain is often such a relief. I'd rather not know how much I'm hurting, even when bedbound from pain, because then it is more 'real'/overwhelming/large component of my life"

(Julie, interview 2).

The sensation of BDSM pain played an important part in control and engaging with the body, for several participants. As Natalie explained, BDSM is a reminder of the capacities of her body, rather than the limitations she is often faced with due to fatigue, which are often frustratingly unpredictable due to the reliably unreliability of her chronic illness.¹⁹⁰ In 'taking' a spanking, or engaging in rough play, and therefore

¹⁹⁰ See p.235.

enduring the acute pain that results, Natalie is able to re-establish her body as capable;

"it also makes my body feel stronger; I tense up, and absorb the impact [of being spanked] and that sort of strength, maybe endurance, makes me feel good" (Natalie interview two).

This does not mean that BDSM sex is the only method of re-establishing a sense of bodily capacity available to chronically ill or disabled people; it is one that Natalie enjoys, while others may prefer more 'vanilla' sex, a sport, or a more sedentary hobby. The important factor is one of a capacity for *pleasure*, rather than endurance or pain.

The sensation of pain itself, as already discussed,¹⁹¹ is tightly controlled within BDSM play, as only particular instruments or methods of pain creation are used once the scene has been agreed upon, and therefore, as Michelle explained, the pain from play can feel very different to the already present chronic pain;

"It's different to the pain that's already in my body, and I think that's what makes it bearable, in a way" (Michelle interview 1).

¹⁹¹ See pp. 266, 276.

This difference in sensation is still understood as ‘pain’ with a strict medical interpretation - a triggering of receptors and a firing of neurons¹⁹² – but a broader interpretation of these sensations gives a very different understanding, one that is dependent on context and intent as well as social constructions of pain itself. The difference in sensation is important to Julie, who explains that:

"The focusing pain calms me, the sensations aren't as deep and pervasive as in chronic pain, the pain is specific. I can appreciate it changing sensations, the pain peaking and troughing. I react in many ways to kink pain, it invigorates me, it turns me on, it allows me to breathe deep full happy breaths. My body doesn't cope very well to non-kink, non-chronic pain, it tends to exaggerate the sensations, making a papercut seem highly painful. It goes into shut down mode quite quickly in these situations" (Julie, interview 2).

The context of pain is particularly important to Julie; that she has consented to pain does not make it less *painful*, because, as she explains, living with chronic pain has made her more sensitive to pain – an experience described in medicine as ‘priming,’ whereby the receptors and neurons involved in sensing pain are already close to being triggered due to chronic pain, and thus relatively minor events are felt more strongly (Denk *et al.*, 2014). However, a strictly medical understanding would make Julie *less*

¹⁹² See pp.**Error! Bookmark not defined.**, 96.

inclined to engage in BDSM; the assumed aversive nature of pain experience would conclude that she would find BDSM too painful to engage in, especially as she is 'primed' to experience higher levels of pain. That Julie describes the sensation as pain means that it is pain – but a form of painful sensation which is not aversive, and is, for Julie, positive – invigorating, arousing, calming – and helps her to engage with her body.

In re-engaging with pain as sensation, participants used BDSM to speak back to pain, as well as welcoming sensation; they are using the capacities of their bodies to bring them pleasure, and to have a positive experience of pain. As Catherine explains;

"There's that thing where chronic pain ... it becomes extremely negative and extremely like there's a feeling of just tiredness associated with it and kind of often getting to the end of your tether with it and... a very negative relationship and possibly that having a negative effect on... on being in your body, like I was saying.... But the emotions I associate with pain in kink are sort of stimulation especially. Much less of a sense of inconvenience because if anything seems wrong then I can ask for it to be stopped.... And, like, everything else can be shut out and I can be very, very present. Which is... is... yeah, presumably other people who are not kinky find that in other places, other things. And yeah, it's much more of a sort of malleable thing that I can make work for me and that is sort of very positive" (Catherine, interview 1).

The idea of making her pain work for her – controlling pain and how it is experienced, rather than pain dominating her actions – is an important part of Catherine’s chosen way of controlling pain, alongside more normative pain control methods. For Natalie, inducing pain through BDSM worked for her in another way;

"I have very low blood pressure and can faint when I orgasm (when things are bad, I can faint when I sneeze!). This is a little dangerous, but it is also psychologically unpleasant and trigger the scant remains of my PTSD. Erotic pain is something which can help keep me conscious" (Natalie, interview 1).

Several participants brought up that they were using BDSM pain in multiple ways, having consciously thought through their reasons for engaging with BDSM, and with pain play in particular – as previously mentioned, self-awareness was deemed important for engaging in BDSM,¹⁹³ as well as for living with chronic pain. For some of the participants, pain play could serve, very literally, as pain relief – as Charlie explained;

"In any sort of kink or sex kind of play ... sometimes [they]’ve been able to, uh, extend the period between using analgesia because of the impact of the endorphins, and just, whatever" (Charlie, interview one).

¹⁹³ See p.283.

Charlie identified flogging and needle play in particular as having an effect on pain sensation. They explained that this meant having pain caused in a particular area (away from the original injury site) as a part of play, which in turn helped to dull the sharper sensation they feel due to nerve damage around the injury site. This could also be combined with what they called “*desensitisation work*,” (Charlie, interview two), a gentler, therapeutic touch on the areas of nerve damage;

“The desensitisation work was secondary to the pain play, and relied on the biochemical and whole body feeling changes of the preceding pain play to be explored” (Charlie, interview three).

For Charlie, desensitisation work was a methodological, carefully thought out, and purposeful use of BDSM pain to help them live with their chronic pain. This use of pain in pain management is not unheard of, although percussion treatment for painful amputation stumps is practiced much less than it was in the mid-20th century (Bourke, 2014). Natalie also reported that orgasm from sex (whether including BDSM or not) gave her a measure of temporary pain relief, and sex with BDSM resulted in stronger orgasms, and thus more effective relief – although it was also more tiring for her, meaning it was more costly in terms of fatigue afterwards. Rita also experienced a measure of pain relief from BDSM play;

“[The pain] aches less, primarily. I think often because I’ve been maybe in the sort of very relaxed headspace, possibly my muscles are more relaxed or... But

sometimes it feels like the one pain has driven out the other, and then once the... once the kink pain has started to fade, there's still less of the existing pain" (Rita, interview 1).

For other participants, kink pain could overlay – not quite replace – chronic pain; in its urgency and acute sensation, it pulled attention away from chronic pain. Acute pain in a controlled situation allowed for a control of pain, again welcoming in sensation, reshaping the context. Edward explained that BDSM play more generally – not just pain from play – could act as a distraction, taking his mind off of his pain temporarily, as he was focused on performing tasks for his Mistress. This drawing of focus away from chronic pain was also experienced by Charlie, who explained when asked why they liked BDSM;

"It becomes very – so whilst I can enjoy the sensation, but sometimes I can also hate the sensation, but – enjoying hating it sometimes as well. But also it – it does become that focus, it takes away from – I suppose other pain in some ways" (Charlie, interview 2).

This, combined with the feeling of having successfully endured the scene, was what Charlie identified as their main reason for engaging in BDSM. The combination of forcing attention away from pain, but within a space where pain can also be reacted to and made public may seem contradictory, but the two processes work side-by-side

by creating pain that must be reacted to, pulling the focus away from *containment* and onto expression – and thus into relief. This is particularly important for Catherine, who struggles to push her focus away from her pain;

"I would say that I'm not very good at the consciously pushing-away part. If it's happening semi-automatically, I think I'm really good at it. As soon as it's hard to deal with, I end up going for painkillers (or alcohol if it's in the evening, or just going to sleep, or what have you)" (Catherine, interview 2).

While BDSM play can be read as a space to reclaim normal humanity through enacting and controlling pain,¹⁹⁴ BDSM is outside of normative sexuality, and therefore normal humanity cannot be reclaimed by engaging in BDSM. However, the participants felt themselves to be already outside of the normal human because of their disabilities and chronic pain; they cannot reclaim normal humanity without becoming non-disabled; the ideal of able-bodymindedness and normative sexuality is forever beyond their reach. Their decision – and desire – to engage in BDSM play is instead a performance of abnormality, a performance of queer/crip sexuality. Several of the participants felt that being disabled made it easier for them to engage in non-normative sexual practices – including BDSM, but also having polyamorous relationships – because they are already cast as abnormal, and they have no desire to

¹⁹⁴ See p.276.

become normal, to be rehabilitated. Just as the non-disabled cannot perceive of themselves as disabled (Kumari Campbell, 2009; Wendell, 1996), disabled people cannot perceive of themselves as non-disabled, except in the past; I would not be *myself* if I were not disabled, as my bodily experience of chronic pain and disability has shaped who I am, shaped my phenomenological self. BDSM exposes being normal as not just impossible, but also as *unwanted* – and for participants, embracing abnormality is not just possible, but necessary. Thus, in deciding not to strive for normality - to not fall in with the societal push for rehabilitation – the participants are re-establishing their phenomenological self, controlling their pain – or not controlling it – as they choose, rather than just when, and how, control is required, performing normality when it is useful, when being read as normal gives them an advantage (although as discussions of pity and others’ readings of their bodies showed, participants sometimes performed normality at unexpected times) – and then performing abnormality when they felt comfortable or safe to do so, or when being abnormal is advantageous.

Conclusions

This chapter has demonstrated a complex relationship between chronic pain, BDSM, and different notions of control, revealed by the narratives of participants. The theoretical significance of the notion of control developed in this chapter is in part in developing a notion of control that acknowledges the central role control of the bodymind plays in normative ableist ideals, but also in part in acknowledging the complex and frequently contradictory experience of engaging with control. In both parts, *control* is a very wide term; it includes containment, but also release, comportment and also agency within ableist social structures – and control includes control over the bodymind, but also control over how the bodymind engages with others, and the environment (and vice versa).

As noted at the beginning of the chapter, finding a term was not easy, and the use of *control* does not necessarily sit well at all times. This may be because participants' engagement and performance of control could be unquestionably normative – a deliberate choice to strive for control as a way of surviving, but also as something they wanted for themselves. Control is not easily crippled; a crip bodymind can perform control and it is hard to see if that control is normative or crip in its performance – although perhaps in acknowledging the complexity of control, rather than assuming it is always necessary and desirable, we begin to develop a notion of crip bodyminds

where there is space for living with pain, acknowledging that experiences of chronic pain are never simple or straightforward, and sometimes those experiences include a need for control, even if the methods of control are decidedly non-normative.

The narratives of control differed widely at times, and at others were very similar, but there were several themes in common. Firstly, the narratives revealed the importance of control of emotional responses to chronic pain – and pain in general. Negative emotional expression is not particularly acceptable in most social spaces, and even in private spaces, as people do not want to confront the idea of pain. Several participants used BDSM to make a space in which they could react to pain with much less control, knowing they had willing witnesses in that space. This tactical performance of emotion – tightly controlled when necessary, and uncontrolled at other times – was paralleled as a part of negotiating medical care and the acknowledgement of their disability by others.

In addition to control, BDSM served several other purposes for participants – including being a pleasurable experience. Making pain in BDSM gave a sense of control over the bodymind, of control over sensation. BDSM was also a space to forgo control, and to re-engage with the body – due to the aforementioned space to react fully to pain. Finally, BDSM was used to control pain in a very direct sense – by altering the

sensation of chronic pain, or by temporarily replacing chronic pain with a much stronger acute sensation.

The narratives told in this chapter also revealed how intimately self-control is tied up with notions of the disabled body as leaky, and thus as abject. Abjection, and its relationship to crip, is where the next chapter will start.

Chapter Seven: Abjection, Analgesic Culture, and Crippling Pain

This chapter explores how pain is made abject, building on notions of abjection detailed in chapter one¹⁹⁵ – and why there is pressure to reject one’s own pain as well as that of others, which pushes those living with chronic pain to be silent, as well as to engage in endless seeking of cures. Then, in turning once again to participants’ narratives of BDSM and pain, I build upon the notion of control from the previous chapter to question how participants crip pain.

Abjection

The disabled bodymind is an abject one¹⁹⁶ (Kumari Campbell, 2009; Tyler, 2013), and all the participants had experience of being the socially abject object – particularly when it came to expressing pain, or revealing their disability. They experienced being the object of disgust, of having value judgments made about them, and of being

¹⁹⁵ See p.65.

¹⁹⁶ See p.65.

treated as 'lesser,' as inhuman. Becoming and being abject is a complex experience to draw out of participants, as being the object of disgust is uncomfortable to recall, and also lays one open to further abjection, particularly if one does not perform a suitable response to being made abject by others.

People are expected to reject pain – pain is socially constructed as an unwanted, aversive, sensation - particularly because pain is a risk to bodily integrity; experiencing pain is associated with injury and wounding, and hence the escape of bodily fluids (particularly blood, but also tears). Pain is a disgusted object, constituted by the subject “though the act of being disgusted” (Tyler, 2013, p. 24), and this constitution is habituated through repetition; pain is automatically disgusting, awful, horrifying – and the more it is rejected, the more disgusting, awful, horrifying it becomes. However, with chronic pain, because it has no obvious external cause, and because chronic pain becomes a part of the phenomenological self, when others react with disgust it is as though they were reacting with disgust towards the individual with chronic pain – rather than the sensation – especially when combined with wider ableist social structures that reinforce the ‘better dead than disabled’ message underlying ‘sympathetic’ statements along the lines of ‘I wouldn’t be able to cope if I were like you.’

Pain is an aversive sensation, and the assumption that it must always be so follows Scarry's thinking when she writes that any experience that does not include aversive feelings towards the sensation cannot be called pain; "pain is a pure physical experience of negation, and immediate sensory rendering of 'against' ... Even though it occurs within oneself, it is at once identified as 'not oneself,' 'not me,' as something so alien that it must be right now gotten rid of" (Scarry, 1985, p. 52). Thus, in order to be believed to be in pain, one must be heard to wish to get rid of it *immediately* – as long as the pain is being experienced, the primary concern of those in pain must be to stop the pain. Living with chronic pain requires a performance of self-disgust – a disavowal of pain, a repeated statement that one does not want to live with disability – but this performance does not mitigate the risk of being abject; expressions of pain continually re-open the space for becoming abject by forcing those witnessing the expression to acknowledge their pain. At the same time, *not* performing self-disgust and not disavowing pain opens the person up to becoming abject, although for different reasons – because in not rejecting their painful self, they have not embraced rehabilitation or tried to be properly human.

Expressing pain reminds the witness of the possibility not just of their own pain, but that they too could become objects of abjection. As Charlie explained;

"People don't like to think of you in pain and not be able to do anything about it. People don't like to think about the concept of pain in case they might

experience pain. You know, it can be very... people that care about you might want to do something about it, people that are a bit more self-centred might be, like, 'Oh gosh, I can't deal with this person in pain, it just makes me think about pain, I don't want to think about pain'" (Charlie, interview 2).

There is a power in transgression, in abject emotions (Donaldson and Prendergast, 2011), and in not rejecting pain, in embracing becoming abject – but this is not always enough to balance out or overcome the social pressure of being abject; there is a continual balancing act between embracing the abject self and rejecting pain.

Pain is not experienced in isolation, and rather than taking Scarry's approach that pain is inexpressible and incomprehensible (Scarry, 1985), I take Patsavas' view, when she argues "for a queercrip understanding of pain as a fluid, relational, and—to borrow Margrit Shildrick's understanding of leaky bodies — [a] leaky experience that flows through, across, and between always-already connected bodies" (Patsavas, 2014, p. 213); pain as fluid echoes the understanding of pain as *a* fluid to contain, and an object of disgust and abjection. However, because chronic pain does not always come with injury visible to the outsider – or at least the outsider who is not also living with chronic pain - it must be made visible, and must be shared *deliberately*; when responses to pain can be controlled and contained, then pain becomes invisible and

unshareable. Because of the need to perform being normal¹⁹⁷ and avoid becoming abject, some participants chose to limit how much they shared their pain, and with who. Julie, in particular, kept quiet about her chronic pain much of the time;

"People don't see my chronic pain. I avoid admitting the levels it is at. For fear of some level of bad response. Because the "aww, I'm sorry" frustrates me, the "you must be weak" hurts me, and the "stop complaining" breaks me. So I don't accept it at some level, I certainly don't project it outwards unless I have to. So nobody validates that chronic pain. Out of my own choice and so they just see me and don't ask questions" (Julie, diary).

Julie notices that in keeping quiet, her pain is not *validated*, it is not observed – and thus is not real to others; for everyone except Julie, her pain ceases to exist the moment it is not spoken of – and Julie is aware of this, deliberately exploiting others' tendency to ignore the possibility of pain (for Julie, for themselves) in order to conceal her pain – not because she suspects they don't believe her, but because their reactions to her pain turn Julie from a person to an object of abjection, and it is this experience that Julie wishes to avoid, feeling that she cannot be seen as herself while also being abject.

¹⁹⁷ See p.59.

At the same time, Julie is abjecting herself; she is horrified by her own pain, and refuses to fully accept it, fully engage with it – not just to protect herself from pain, but because she is so horrified by others' abjection of her pain. In effect, other's validation of her pain holds a mirror up to Julie; she can almost ignore her pain – or at least ignore aspects of it, can live with it – until others' reactions remind her that she is abject, that in order for her pain to be real she must be an object of their horror, and an object of her own horror as a result. Julie's horror at becoming abject becomes a horror of her bodymind, of her self. The two threads – others' abjection and abjection of self - are knotted and tangled together.

Becoming an object of abjection by others feeds back into regarding oneself as abject; writing about re-reading an entry in a pain diary she kept as a young woman, Patsavas writes "I internalized the shame and responsibility for my inability to get rid of the pain, and for the pain that I assumed I caused to others. Rereading these entries, I see not only how deeply I felt a sense of failure but also how clear it is that we never experience pain in isolation. How differently might I have felt the pain in a context where interdependence is acknowledged and valued?" (Patsavas, 2014, p. 209). This is felt most strongly in situations where one is expected to perform self-abjection, to make oneself abject in front of others, as "being seen as a strong and skilled member of society clearly makes one feel differently about oneself than being seen as one

looked down on. Such differences in relational ecologies of sensation effect different processes of subjectivation" (Hickey-Moody, 2015, p. 145).

Analgesic Culture

The increasing number, and commercialisation, of various 'cures' for "proliferating zones of bodily and affective imperfection" (Mitchell and Snyder, 2015, p. 39) is reflected in the range of treatments and rehabilitative practices available to – or pushed on to – people living with chronic pain. Practices I myself have been prescribed by various medics include: physiotherapy, cognitive behavioural therapy, graded exercise therapy, hydrotherapy, mindfulness therapy, mindful cognitive behavioural therapy, weight loss, four different antidepressants, and three different painkillers, along with additional medication to manage the side-effects of those painkillers. Non-medics have recommended everything from acupuncture and massage to various (inevitably expensive) diets and innumerable food restrictions. This list demonstrates not just how the abjected body is made a part of neoliberalism (Mitchell and Snyder, 2015), but how medicine turns pain from a meaningful personal event into a technical matter to be fixed (Illich, 1995). However, the range of treatments results in increased pressure to try each and every one, each one containing the possibility of cure, each treatment and attempt reinforcing that a life

with chronic pain is no life at all – that until they are completely rehabilitated, you are not quite properly human, not quite properly valid. The emphasis on cure and treatment pushes responsibility for ending pain onto the person living with pain, and ending pain is recast as a personal choice (Patsavas, 2014), remaining in pain and disabled is a personal failure; the person who refuses to try yet another treatment is a failure, but so is the person for whom a treatment doesn't work – it fails not because it doesn't work, but because they haven't tried hard enough, thought positively enough, or done the treatment properly.

Pain is equated with suffering,¹⁹⁸ a person in pain is assumed to be suffering, and assumed to want their pain to be taken away, to be cured. Chronic pain is assumed to be worse. Furthermore, the non-disabled person assumes that the disabled person, the person in pain, cannot sustain their disabled/painful state, that their state is one of intolerability, of ontological impossibility. This is what underlies what is referred to as 'analgesic culture,' where "pain has ceased to be conceived of as a 'natural' or a 'metaphysical' evil. It is a social curse, and to stop the 'masses' from cursing society when they are pain-stricken, the industrial system delivers them pain-killers ... Pain has become a political issue which gives rise to a snowballing demand on the part of anaesthesia consumers for artificially induced insensibility, unawareness, and even

¹⁹⁸ See pp. 128, 92.

unconsciousness" (Illich, 1995, p. 135). While Illich's suspicion of medicine can read as a little over the top, his contention that medicalisation of pain has meant that it is understood as 'curse' that those in pain *must* be freed from in order to improve society as a whole is reflected in both ableist discourses of disability in general, and the participants narratives of how others perceive their pain. As Charlie said,

"People don't want to hear about it because they can't do it... anything about it. Nobody wants to hear about it, there's nothing that can be done about it. How do you express it? What do you do with it?" (Charlie, interview 2).

Patsavas, in response to Scarry's contention that pain is beyond language (1985), argued that pain is unshareable because of ableism (2014), because of the assumption that being in pain is ontologically intolerable,¹⁹⁹ that living with pain is unendurable and unwanted, undesirable – and because it is fluid, it is transferrable,²⁰⁰ that by listening to the pain of others, we are not just reminded of our own pain, but risk experiencing pain, as though pain were contagious. This creates a twofold problem; that those who must listen to others talk of the pain have a standard of behaviour that they hold 'pain sufferers' to – assuming they must be incoherent with pain, beyond

¹⁹⁹ See p.44.

²⁰⁰ See p.302.

rationality – but also that they do not want to listen too closely, for fear of catching pain. As Catherine explained,

"I think ableism about pain is such a problem e.g. with medical doctors. If they've never had it, they don't see why you need painkillers. The number of times I've had to argue for painkillers because if I'm up and about and at the doctors, they think I don't need them" (Catherine, interview 2).

Even as people in pain are denied painkillers for their failure to properly perform pain, or because that performance is disbelieved because of their gender, race, or age,²⁰¹ or because doctors fear they will become addicted (Morris, 1991), it is assumed that those who are in pain must want nothing so much as they desire to have their pain cured, even if it harms them in other ways – the desire for cure supersedes all others. As Patsavas explained, “the uncomplicated quest for a medical cure makes curing pain not only desirable but also compulsory” (Patsavas, 2014, p. 208). For David, medication created other issues,²⁰² and Charlie found medication difficult, explaining that while they felt less pain, they were made sick in other ways;

"I've taken medications that have not suited me, and I'm not going to take them because the overall impact... They might have dealt really well with the

²⁰¹ See p.106.

²⁰² See p.246.

pain, but I might not be able to focus or something, or, you know, might not be able to drive or whatever. Just that kind of... So I'll take stuff that is maybe going to deal with less of the pain, but at least I can function. So it's always a balance and it's always about optimising for what you want to do in that moment, which changes over a lifetime and stuff" (Charlie, interview 2).

For Charlie, this meant they had to be careful to manage their pain in multiple ways, to take time to manage disability²⁰³ and to pace²⁰⁴ so as to reduce the chances of a pain flare. Being in pain was not impossible for Charlie, but it was made difficult by ableist assumptions about how they should manage – and want to manage – being in pain and being a ‘functioning’ proper human.

Care and Suffering

The notion of care encompasses a wide range of acts and spaces, but this section will address two main areas: medical care, and care within personal relationships. While disability rights has pulled away from, and frequently opposes, the medicalisation of

²⁰³ See p.248.

²⁰⁴ See p.250.

care²⁰⁵ – arguably a little too much at times (Kafer, 2013) - chronic pain still lies firmly within the medical sphere.²⁰⁶ Thus, the problems, as well as advantages, of medically-situated care need to be addressed. Access to medical care is unequal; not all the participants felt they had access to adequate medical care, particularly chronic pain specialists. This unequal access can be geographic - not living near a specialist – as well as financial. Unequal access also lies in discrimination and the perceptions of carers and medics; just as women and people of colour are less likely to be believed when reporting care,²⁰⁷ gender and sexual minorities are less likely to receive adequate care (Jain, 2013), or face discrimination (Earle, 1999). As Jain observes, “minorities who have experienced, or interpreted, discrimination are less likely to visit doctors for check-ups or to follow up on health concerns” (Jain, 2013, p. 39), and this then leads to additional problems, such as illnesses not being diagnoses until later stages and a lack of necessary medication. Medical care is not free of value judgements. For Charlie, access to care is complicated not just by being trans, but by being autistic²⁰⁸, as they explain;

²⁰⁵ See pp.46, 116, and 119.

²⁰⁶ See p.96.

²⁰⁷ See p.106.

²⁰⁸ See p.228 for profile, and section starting on p.329 for more on autism in the research.

"I find it difficult to sometimes be taken seriously or get the support or care I need sometimes by that, because I don't express my pain in ways that are socially the norm" (Charlie, interview 2).

The pressure to express pain appropriately²⁰⁹ and, when pain is expressed, the resulting stigma of failing to contain pain (Nielsen and Fernandez, 2010) leads to inadequate care when medics act as gatekeepers to specialist care, as well as acting as care providers themselves.

Julie and Michelle, however, both felt their access was limited because of their diagnoses – that once they had been given diagnoses, that was it, they were on their own, because no 'cure' could be given, and they had no prospect of 'improvement' or successful rehabilitation. Both Julie and Michelle – and also Charlie and Rita, to lesser degrees – experienced what Bury refers to as a 'crisis of credibility,' which "may occur if the individual continues to report problems after their 'share' of attention has been used up, or when they have been placed in a category (e.g. 'successful operation') which closes off avenues of support and information" (Bury, 1991, p. 457). The acquisition of a 'dustbin diagnosis' – a broad 'syndrome' rather than a specific illness,

²⁰⁹ See pp.107, 117, and 269.

or a diagnosis for which no cure exists²¹⁰ is often experienced as a dismissal, especially as the diagnosis itself can take years of effort on the part of both medics and patients; medics' frustration with the lack of cure may spill over to frustration with patients, who are themselves frustrated with the same issue (Patsavas, 2014; Tomlinson, 2013). The difficulty is compounded by a lack of rehabilitation or long-term 'pain management' programmes and increasing pressure on medics to limit the prescription of opioid painkillers (Morris, 1991; Sheppard, 2015a).

This may seem at odds with the commodification of pain in analgesic culture.²¹¹ However, as Patsavas explains, narratives of ending suffering and the dangers of opioid painkillers "work together to bind the chronic pain 'sufferer' within a discursive system that offers a cure through consumption, condemns the individual for using that cure, and holds the individual responsible when the cure does not work. Living a life without pain amounts to an imperative that captures the person in pain within a system of individual responsibility and 'compulsory able-bodiedness'" (Patsavas, 2014, pp. 209–210 quotes original). Catherine mentioned that she felt that her doctors had recently become less willing – or less able, in that strictures have been imposed on

²¹⁰ See pp. 119 and 312 for the focus on cure; examples of such diagnoses include M.E./C.F.S., and fibromyalgia.

²¹¹ See pp.72, and 254.

them - to prescribe painkillers, which was affecting her wellbeing as well as her confidence in the care provided. This complex tangle of pressure to manage pain appropriately through medicine, to express pain appropriately, and to be rehabilitated or cured properly works within a wider ableist discourses to limit care to medicine, dismissing non-medical care, but also condemning the individual when medical care fails them.

The condemnation of those whose medical care has failed to rehabilitate/cure them spreads outside of the medical sphere, just as illness and incapacity affects multiple aspects of people's lives, including their relationships. As Julie wrote,

"I can't just park my health problems to one side and enjoy sex/wank/kink/pain/whatever. They have to come too. And that's a big ask of others. Because nobody likes to think that their nudging to me to go for a third orgasm with an element of pain play involved results in a potential stroke"

(Julie, diary).

While Julie is talking specifically about uncommitted, non-monogamous relationships based around BDSM play, her words echo the discourse that tells disabled people that their disability makes them undesirable partners - especially if they require care or assistance (Gillespie-Sells *et al.*, 1998; Shakespeare *et al.*, 1996). The dual assumptions that disabled people require their intimate partners to also be carers, and that care work is demeaning and disgusting whether it is paid or not, work against disabled

people, but also limits what is perceived of as care. Within these assumptions care consists of physical labour and wiping away bodily fluids, but not of slowing your walk to match a different pace, or sitting with a person experiencing a panic attack, while being the object of care, being cared for, is positioned as demeaning, discomforting; care is not an act of love or of recognising another's inherent human dignity,²¹² or even meeting another's most basic of needs – care is inhuman and disgusting.

Price (2015) illustrated a reimagining of care as collective which is focused on non-medical care, but when taken alongside Kafer's (2013) call for space for medicine within disability rights and crip spaces and calls to acknowledge the interdependence of life (Crow, 1996; Morris, 1992; Wendell, 1996), her description paints an arresting image of collective care which "means moving together and being limited together. It means giving more when one has the ability to do so, and accepting help when that is needed. It does not mean knowing exactly what another's pain feels like, but it does mean respecting each person's pain as real and important. Finally, care must emerge between subjects considered to be equally valuable (which does not necessarily mean that both are operating from similar places of rationality), and it must be participatory in nature, that is, developed through the desires and needs of all participants" (Price, 2015, p. 279). This reimagining of care has space for complexity, for acknowledging

²¹² I recognise 'dignity' is itself a contentious topic (Frazee, 2014).

that disabled people can perform care for others. Natalie's description of her relationship with her partner, who is also disabled, comes close to Price's description; she trusts that her needs will be heard, and met – but also that her partner will express his needs, and trust her with those needs – and for them, this comes down to communicating their bodily states;

"It's something we have to discuss a lot, because we're very tactile outside of love-making and we both have times when there's a part of our body we can't stand to have touched. Other times, there are parts that benefit greatly from touch, such as rubbing a cramping muscle etc... So we talk about it all the time - not analytically, not in a self-pitying way, but we keep one another informed"
(Natalie, interview 1).

Crippling Pain

Chronic pain presents problems to normative understandings of pain, which present very limited discourses about what pain is, why it occurs, and how it can be responded too. Those who live with chronic pain are often pushed into responding to their pain in ways which enforce individualism, deny interdependence, and leave little room to find meaning in pain, or make their own meaningful responses. Pain is regarded “as a systemic reaction that can be verified, measured, and regulated” (Illich, 1995, p. 137),

with emphasis on its usefulness only for diagnosis, rather than a meaningful experience in itself. Increasingly, people living with chronic pain are seen as responsible for managing their own pain, and responsible for their disability in the first place, through their personal failure to 'look after' their health and then engage in rehabilitative practices.

People who do not live with chronic pain regard being in pain as dehumanising (Patsavas, 2014; Sheppard, 2014b), as ontologically intolerable, if not ontologically impossible, and that those who do live with chronic pain exist solely and continually in a place of suffering. "The cultural discourses that frame pain as an isolating, devastating experience crystallize to prevent the exploration of alternative explanations for why chronic pain might be (or seem to be) unliveable" (Patsavas, 2014, p. 204); those who regard pain as other than wholly intolerable are regarded as perverse, (Newmahr, 2011; Patsavas, 2014), or, more commonly, assumed to be lying about being in pain (Nielsen and Fernandez, 2010). The assumption that being in pain is intolerable, and reduces the person in pain down to an inhuman, animalistic, sufferer means that when people in pain present as anything other than inhuman they are disbelieved, even though presenting as inhuman means they are stigmatised and made abject²¹³.

²¹³ See pp. 65, 299.

This is not to say that the experience of chronic pain is not, and cannot be, devastating and difficult; Julie's narrative of mourning her past and no-longer-possible futures is a narrative of her devastation, but, I would argue as Patsavas does, "that when cultural discourses construct pain as the cause of feelings of devastation, they oversimplify complex cultural, historical, and political phenomena. More than that, they prevent us from examining the structural conditions that make experiences of chronic pain tragic" (Patsavas, 2014, p. 204). This means that while chronic pain experiences can be devastating, the sensation of pain alone is not the sole cause of that devastation – there are structural conditions that mean living with chronic pain can be devastating. The abjection of people who speak of their chronic pain, and the assumption that chronic pain makes one inhuman are important structural conditions affecting how people living with chronic pain experience their pain – as are the structures of pace of life and the demands of appropriate self-control. Analgesic culture relies on a discourse of pain as meaningless and devastating to support the push towards eliminating pain, and structural forces that support pain as devastating – and prevent alternative narratives from being heard – do just that.

As Kumari Campbell explains, "it is problematic to speak of bodies in their materiality in a way that distinguishes between emotions and cognition. This generative body is shaped by relations of power, complex histories and interpreted through a bricolage

of complex interwoven subjectivities" (Kumari Campbell, 2009, p. 14). Thus, chronic pain is a part of these interwoven subjectivities, the reconstitution of the self – as discussed in chapter five.²¹⁴ However, rather than a remaking of the self *after* pain, as occurs after acute pain, chronic pain's ongoing experience – with no expectation of ending²¹⁵ – means that the self is remade *with* pain. Charlie explained that when;

"You can't rely on your body to do what you want it to do any more, your confidence and your sense of control over your own life, it changes" (Charlie, interview 1).

Young points out that "because the body as a locus of self is imaginary ... [we] are complicit in the invention of [our] own subjectivity" (Young, 1997, p. 81), thus, when Charlie's sense of self-control changes, their sense of *self* changes.

Charlie was aware of how living with chronic pain had changed their phenomenological self;

"If somebody asks me how I am, and I say, 'Oh well, I'm in a lot of pain,' but, you know, that would be the same answer every day. It's just, like, where does that go? It doesn't go anywhere, and... stuff like that. So it becomes a norm as well. So it becomes something that is part of the norm that isn't spoken about

²¹⁴ See p.238.

²¹⁵ See p.86.

as news because it's part of the norm, and a lot of other people forget that's your norm" (Charlie, interview 2).

This new norm, being in pain, is the phenomenological self remade with pain. Just as new pain makes us aware of the body (Scarry, 1985; Young, 1997), once that awareness has 'settled in' to being a part of the everyday experience of the body, we cease to consider it as relevant, and it is only when chronic pain changes – lessens or worsens – that we become aware of it once more. In exploring participants' narratives of sensation, I have explored how they have actively – and not so actively – remade themselves, and come to live with pain.

Sex

Within BDSM scenes, disabled people are active participants, but not 'typical' scene members; some scenes situate disabled people primarily as receivers of charity by BDSM scene fundraisers (Beckmann, 2005) – notably through the Sex Maniacs' Ball and Outsiders Club – which others disabled people. Some scenes and scene members may be welcoming to disabled people, but others may be less so – especially scenes which emphasise "pornonormative" (Newmahr, 2011) displays of sexuality, where

desirable partners tend to be non-disabled and normatively attractive.²¹⁶ Some participants who did join their local scene found their local scene welcoming, others less so, particularly when it wasn't physically accessible, or was impractically far to travel.

Within some BDSM scenes, as in wider society, there is often the perception that disabled people only have romantic and sexual relationships with other disabled people (Gillespie-Sells *et al.*, 1998; Shakespeare *et al.*, 1996), or that those who have relationships with disabled people are devotees, or disability fetishists²¹⁷ – although there is broader acceptance of disability fetishes within BDSM. The participants had a mix of relationships; Edward's play partner at the time was also disabled, which affected the practicalities of their play together, but that he saw as largely unimportant in terms what he desired in a partner, while Natalie and Rita found that having a disabled partner helped communication within the relationship. It is interesting to note that both women had previously been in abusive relationships with non-disabled men, in which they were forced to engage in BDSM; both placed high importance on being able to effectively communicate in order to practice BDSM once again. For Natalie, having a shared experience of embodied as well as social disability

²¹⁶ Young, slim, able-bodied/minded, white, and so on.

²¹⁷ See p.136.

(she and her husband have the same diagnostic label), and hence of being abject and regarded as abnormal, made her feel more able to trust her partner, but also able to engage in power play. Natalie feels that the shared experience of bodily limitations and capability has meant that they have a greater awareness of how strong they both feel when sexually aroused, but also that she is able to trust him enough to be submissive, as he has also experienced what it is to be powerless as a disabled person.

Bodies in BDSM and bodies in disability are unruly, uncivilised bodies (Beckmann, 2005); when disabled bodies engage in BDSM, they do not become *more* uncivilised (as bodies are either uncivilised or not), but they reimagine what it means to be sexual and what it means to be in pain. Flanagan and Rose's BDSM performances²¹⁸ are examples of this, as "Flanagan and Rose produce meaning that sustains Flanagan's life with and in the disabled body and opens the possibilities to enjoy this body and to derive pleasure from it for both himself and his partner. Cultivating the (eroticised) pain in the S/M practices (both public and private), becomes not a matter of simple domination or control of the pain, but a much more complex strategy of transforming and integrating the pain ... [and] turning it into a subject-matter of his "technologies of the self" (Foucault, 1988)" (Kolářová, 2010, p. 49). For the participants, integrating pain through BDSM – and integrating BDSM through pain – was often less publicly

²¹⁸ See 172.

performed than Flanagan's artistic work, but was nonetheless a part of their reimagining of their selves as people living with chronic pain. Bauer argues that BDSM, as a "sexuality of excess" purposefully denies and resists explanation – rejects 'why'? (as does Flanagan in his poem (2000) of the same title) – with pleasure serving in and for itself alone, but also feels that certain forms of BDSM play maintain the status quo and reinforces (rather than challenges) established power differentials; "a simple philosophy of hedonism without social and environmental responsibilities as integral components would do more harm than good in the 21st century" (Bauer, 2014, p. 248). Instead, Bauer's participants tried "to create pleasurable yet responsible ways of confusing boundaries in order to open up bodies and connect across differences. While this may seem less exciting to some theorists, I hold that ethical and political considerations, most basically understood as taking into account and being accountable for the consequences of one's actions, such as the effects on others, social contexts and 'natural' environments, are indispensable" (Bauer, 2014, p. 248). This is echoed in my own participants' narratives – it is not just about pleasure, but also about situating the self in multiple contexts.

Julie, whose relationship with her pain and with BDSM was fraught – and unhappy due to her limitations – wanted to find ways to be fragile while also engaging in play, although she foresaw it as requiring flexibility and thought on both her part and on her partners' part;

"Both me and others have to be careful. I don't think they realise how careful at times, but those who I am involved with regularly manage to understand my limitations day-by-day. I think it is fairly obvious in my vocabulary and voice as to how fragile I'm feeling that day" (Julie, interview 2).

This using and contesting of her fragility and limitations by Julie is a part of her reconstitution of the self, of controlling her body again – but also about living with pain, making the pain a part of her, even though it makes her body unreliable, and has had a huge impact on her life. Pain and disability push Julie to become a misfit, a mismatch between “the co-constituting relationship between flesh and environment” (Garland-Thomson, 2011, p. 594), but it also gives her the time and space to become, if not comfortable, then accepting.

Another example of this accepting, and of making pain one of the technologies of the self, is in Natalie and her partner’s life, where they have made use of the concept of safe words – words or actions used during BDSM play to communicate needs without breaking the scene, or to put a quick stop to the scene. Safe words are not unproblematic – there can be pressure to not use them, or to make a boast of not having them (Newmahr, 2011) – but they can serve fairly effectively as a way of communicating needs, as Natalie explained;

"[husband] and I have long used safe-words during non-sexual physical contact. So an obvious one is tickling or similar messing about, but also if we're any

hugging or stroking or just lying entangled with one another, we have words when things become suddenly too painful (i.e. when there's no time or capacity to say, 'Do you mind stopping that now? It's hurting.'). We rarely use safe words in sex - they're there, and they're there for all kinds of sex (since any position or activity risks becoming suddenly very uncomfortable). However, I thought this might be a useful example of something where chronic pain and kink interact; we have thought about safe-words because of kink, but we got good at using them through living with chronic pain (I would say fluent but I can't claim we're perfect with this - we still sometimes say 'Do you mind...' when we're feeling, 'Aaagh, get off!')" (Natalie, interview 2).

The queering/cripping of pain – of making pain work for and with you – is a queering/cripping of the performance of being abjected, it is embracing abjection, embracing a queer and crip selfhood. This same performance can be seen in Flanagan's work, which "embraces the abjected disability. And while the sexual practices of S/M enable Flanagan to transform his physical pain, his engagement with queerness exceeds his individual body (in pain) and stretches to the level of the socially inflected pain of stigma. The transgressive potential of Flanagan's queer gesture thus lies precisely in embracing the disability and sickness to become Sick/Crip" (Kolářová, 2010, p. 45). For the participants, embracing abjection does not mean performing abjection for the non-disabled, but accepting that they are already,

and always, abject under the ableist gaze - and thus they can embrace disability and make it work for them, accept its limitations and discomforts and leaks as a part of their self.

Some of the participants also felt that being disabled helped them embrace BDSM – and vice versa. Edward’s comfort with his BDSM identity was clear in his interviews, and while some of that may be due to the length of time he has been involved in BDSM, having been playing since his twenties and now in his late forties, it is also due to his disability meaning he does not have to perform normative masculinity.²¹⁹ In effect, Edward’s disability means he is already disqualified for masculinity, and thus he feels more able to engage in activities that are not properly masculine – such as being a submissive slave to his mistress. This is not to say Edward does not perform masculinity in other ways – such as in his job, or his clothing – but that he is already situated in a place of failure to be a ‘proper man’ – so why not enjoy it. Natalie’s experience was similar, she felt that being bisexual (and particularly being aware that she fancied girls as a young teenager) meant that she had had the option of normality ‘taken away’ – and thus she was able to embrace disability; embracing disability and bisexuality then meant she was able to embrace BDSM. Natalie has made being

²¹⁹ See p.138.

queer/crip work *for* her, and by embracing her multiple failures of normativity, she has opened up a space for her acceptance of her self.

Charlie felt that there were multiple factors affecting their ability to accept and embrace their disability;

"And I think... so, an existing disability helped me cope with a disability, which is just another layer again, in that sense. Yeah. So, you know, the things that can help people cope can be disability as well. And, yeah, coping with... I mean, there's interactions between everything. I think I was able to resist the medicalization of non-conforming gender because of my experience as a disabled person and trying to navigate and resist some of the medicalization, my awareness of the social model of disability, and just, you know, what kind of medicalized sort of perspectives were going to get applied to my body because I'm non-gender-conforming. I had to resist those. So different things... Yeah."

(Charlie, interview 2).

This is not to say that all disabled people desire to embrace non-normative sexualities; instead there is often a drive to emphasize their normative sexuality – especially in what Natalie described as ‘*disabled people have sex too!*’ articles and programmes – by making a pronounced performance of their straightness (or homonormativity), or continually expressing their desire to ‘live normal lives.’ This almost-exaggerated

performance reassures non-disabled people that disabled people are not *totally* monstrous (although it also serves to reinforce their difference – they would not need to reaffirm their normality if they were normal in the first place) and that normality is desirable, and also serves to reinforce to other disabled people that performing normality, and desire of normality, is the best – indeed only – way to live with disability.

Making Pain

Through engaging in BDSM, the participants are engaging in a process of *making pain to witness*, of making pain visible through participating in acts that are deliberately painful – in contrast to their chronic pain, which has no witness. Making pain is an act of meaningful communication (Price, 2015), but in making pain to be witnessed, to be seen and heard by another, they are drawing the witnesses into their pain, as “the act of witnessing somebody else’s pain ... is a performative act that affects all involved bodies, both in and out of pain” (Kolářová, 2010, p. 47). Making pain to witness is both

a part of controlling the expression of, and reaction to, pain,²²⁰ but also a part of integrating pain into the self.²²¹

Communicating about pain is a part of making pain to witness – for those participants who found their chronic pain impacted their capacities for play (such as how long they could play for, or what form that play could take), communicating pain plays a dual role; they are communicating their play pain, and also their chronic pain. This is not to say communication is always straightforward, as Natalie explained;

"Because we both have chronic pain, we're able to communicate about pain pretty well, and have gradually become more explicit, even though our descriptions are often quite gruesome. With [husband]'s pain, I often try and pin him down to a number between one in ten, but I really struggle to do that with myself" (Natalie, interview 1).

The number system Natalie refers to is an informal variation of the Wong-Baker scale (Wong *et al.*, 2001), and while quantifying pain may make it a little easier for her to understand, as her own and her husband's responses show, it is often difficult for the person in pain to do in a way they are satisfied with. Making pain to talk about – pain that is easier to express, and thus easier to experience – aids in this communication,

²²⁰ See p.276.

²²¹ See pp.238, and 321.

as it is a different experience of pain, an expansion of the vocabulary of pain and a point of comparison, and also a shared experience between the person in pain and the person causing that pain.

Autism

One of the unexpected aspects of the research was the incidence of participants who identified as autistic, or having a diagnosis of Asperger's' syndrome; out of the eight participants, four were autistic.²²² This is higher than expected, given that around 1% of adults in the UK are autistic (Brugha *et al.*, 2009) – although there is evidence that autistic individuals are more likely to have multiple disabilities and chronic illnesses (Treating Autism *et al.*, 2014). Thus, while I did not particularly consider autism in the literature review, I am addressing what was discussed with participants as it is both

²²² From this point, I will use *autistic* to include those who have a diagnosis of Asperger's syndrome; I use autistic people rather than a person-first term ('people with autism'), as that is the preference of the community. I have not differentiated between participants who disclosed whether or not their diagnosis was not 'formal' - i.e. made by a medic - or self-diagnosed.

interesting, and exposes some of the social constructs around pain and sensation that have helped clarify my thinking.

A discussion with Catherine which began with her explanation that she struggled with talking about her body and her emotions because of her autism, and thus in communicating her chronic pain to others, contrasted with Charlie feeling that their autism has given them additional resources to deal with becoming disabled as an adult – as they felt they were more pragmatic, and thus their approach to disability was practical, rather than emotional. However, Charlie also said that this counted against them, as people did not fully believe their pain, as they were not emotional enough²²³ – which is a problem Catherine shared. For Catherine, while her autism presented issues, she felt that a lot of those issues were due to ableism, explaining that

"So, social norms are a mystery for a lot of autistic/neurodivergent people. I think that's linked (though I'm not exactly sure how) with non-conformity around gender norms for a lot of us. (I am personally realising, quite recently, that I have difficulty identifying with gender because it's all based on social norms and I simply do not understand them, on quite a deep level.) So with sexuality, there are a lot of neurodivergent people in same-sex or sex-non-

²²³ See pp. 107, and 267.

conforming relationships, and I think that involves some of the same processes. I never understood why BDSM and similar stuff is seen as breaking social norms. Where do those social norms come from, and what are they for? Obviously I can answer those questions sociologically (heh - that's pretty much why I do what I do), but I can't on a personal, emotional level. These norms are just totally alien. So I think it's possible that some of us are just very non-conforming when it comes to sexual norms and mores, as much as with social ones, and that that may lead to more of us being involved in kink or similar. BUT as I say, totally a personal theory based on anecdotal stuff and vague experience!" (Catherine interview 2).

Michelle, Catherine and David all felt they didn't understand the social stigma of BDSM – they understood that it was considered 'abnormal,' but not *why* social norms rejected certain sexual activities but not others. David also identified a more welcoming attitude amongst BDSM practitioners towards autism that he thought led to greater involvement of autistic people (and disabled people more generally) in BDSM, saying that the willingness of practitioners to explain the 'rules,' as well as the explicit existence of those 'rules' also made him feel welcome.

For Catherine, BDSM was particularly about sensation (it is worth noting that David played on the scene, in semi-public social spaces, while Catherine played only within a

monogamous relationship), explaining that she preferred the stronger physical sensation of BDSM;

“Actively painful stuff in sex does give me much better sensory signals yeah. As in, more ‘straightforward’ signals ... And a lot of the time I want sex to be quite rough even if it’s not ‘officially’ kink and that’s partly because without roughness it’s, eh, a bit nothing-y” (Catherine, interview 2).

Catherine went on to explain that she felt the “better sensory signals” (interview 2) from BDSM echoed her stimming practices, where she found repetitive, almost-painful sensation soothing, helping her deal with sensory overload and the resulting stress. The topic of stimming was brought up in interviews with Charlie and David as well. Stimming, or self-stimulation, is a repetitive motion or sound performed by an autistic individual, and is often explained by autistic people as soothing, calming, or focusing. Examples of stims²²⁴ include rocking, tapping, flapping hands, banging or hitting the head, and repeating particular words or sounds. As autistic self-advocates have pointed out, stimming is performed by non-autistic (or neurotypical) individuals as well – foot-tapping or fiddling with hair or a pen being good examples – but it is often pathologised and read as abnormal when done by autistic people (Price, 2015, p. 20). Price writes that “Stimming... might be read by various observers as impolite fidgeting, a pathological need to self-soothe, or an expression of Autistic identity

²²⁴ Stimming behaviours

(Yergeau, 2011). This example, when considered in the context of audiences who observe the stimmer, illustrates the shape-shifting nature of the misfit. Stimming is a highly contingent phenomenon, contingent not upon a physical metric such as the height of a step, but on the affective response of those who observe and interpret it" (Price, 2015, p. 272).

Other stimming practices, particularly those read as violent, disturbing, or harmful (such as banging their head against the wall, shouting, or hitting themselves) by others are less easily read as 'soothing' or even a necessary expression of emotion or identity, but Price's description of treating even violent behaviour as meaningful illustrates how this could be changed;²²⁵ "To be 'considered equally valuable' when I am in the midst of a violent break means to be treated as someone who is having a meaningful experience, even if my actions are not always safe (and thus sometimes need to be curtailed). That my experience is meaningful does not imply that the person or people with me are able to understand it, but rather that they take for granted it should be understood. Striking my head with a lamp may be undesirable in the sense that it is physically dangerous (and frightening or triggering for those who observe it); however, it is desirable in the sense that it is a meaningful form of

²²⁵ Price is not just discussing stimming, but violent outbursts, psychotic breaks, and other 'symptoms' of neuroatypicality.

communication" (Price, 2015, p. 279). The conception of stimming as harmful is paralleled by the equation of pain with suffering;²²⁶ there is an underlying assumption because some stims may be harmful to the individual, or disturbing to the witness, *all* stims are harmful, just as when because some pain is unwanted and is suffered from, then all pain must be suffering – and the approach to eliminating stimming has been similar to that of eliminating pain, that it must be done at all costs. There is increasing acceptance of stimming (particularly ‘harmless’ physical stims) in view of witnesses, rooted in autistic self-advocacy, but much less acceptance of pain reactions.

There is much less acceptance of ‘dangerous’ or ‘harmful’ stims, particularly those that draw blood²²⁷ and can be read as being ‘painful;’ the assumption is that because the stim appears painful to an observer, it must not just be painful, but that pain must itself be unwanted - not just to aid the discomfort of the observer, but that the person must not, in fact, *want* to stim in that way, or that they must not understand the danger. Harmful stims, those that are assumed to cause pain, are unwanted *because* they cause pain, and such stims are often characterised as self-harm, especially in

²²⁶ See pp.128, 92.

²²⁷ See pp.65, and 302 on fluids and abjection.

‘verbal’ or ‘high functioning’ autistic people²²⁸ who are assumed to be ‘capable’ of understanding harm (or feeling pain ‘properly,’ perhaps). The line between stimming and self-harm is not always a clear one; some stims come with a risk of injury, but I do not wish to equate the two, only to acknowledge the complexity and fluidity of the division. However, I am addressing self-harm here because it was brought up within these conversations around stimming, sensation, and emotion; there is a great deal of difficulty in addressing self-harm, mental health and neuroatypicality within BDSM scenes, particularly as there are valid concerns around how this could lead to further pathologisation of BDSM and practitioners (Barker and Langdridge, 2009). Charlie explained that;

"at one point there was also seeking pain for emotional release, within the sort of self-harm context, bit we were talking right at the beginning, I can't remember which of the questions it was at the beginning that made me think about it – oh, it was about seeking out pain and stuff like that. That was for a period, and, I, I was quite interested in some of the parallels and overlaps, uh, but that was more about emotional release and distraction from emotional pain. But I was kind of aware of the slight kind of tangle, really. Uh – and again

²²⁸ I do not wish to reinforce the concept of autism as a spectrum as it so often carries moral judgement.

that kink of aspect of endurance, of survival, and stuff, so, yeah." (Charlie, interview 1).

Charlie does not feel that kink is a form of self-harm, and we discussed this further, when they explained that;

"And I do think, maybe they are a little bit intertwined, maybe more than people like to think about sometimes, because there is this, you don't want to talk about self-harm within kink, because you want to present kink as a normalised thing [laughs], and it is, but I think there's also an interplay, for me, at least in my own experience anyway, it's that sort of – why do I want to hurt myself? There's all sorts of reasons for that other than just enjoying the sensation ... you know, there's, there's – a lot of it is cathartic and trying to work out other stuff, because, all the other stuff that you can't do anything about, that sort of helplessness stuff, that sort of. So yeah, yeah. That sort of – as you say, appeal of self-harm is very much there, whether I engage with it or not, in that sense, and at the time I did, there was other background emotional stuff going on that there wasn't support for or a resource for or whatever, so it was – it was something more active, but it doesn't mean that I might not have felt it before or since – it's that sort of as it was, yeah," (Charlie, interview one).

Charlie did not explicitly link stimming and self-harming in our conversations, but David did;

"I've [sighs] my masochistic streak has always been a thing – I, I got introduced to kink almost as a way out of self-harming, sort of – friends were aware I was cutting, um – not so much in a self-destructive way, or – but as a way of self-stimulating" (David interview 1).

However, David felt that kink helped him practice potentially-harmful stimming – in his case, deliberate cutting – in a way that was arguably safer and healthier (in terms of tools and aftercare), as well as more open and accepting. David's friends read his cutting as meaningful communication, as needing to be understood and witnessed – rather than stopped – and as such their affective response, guiding him into a 'safer' space, was one of care rather than condemnation. David has since felt that he is able to stim in other ways, to engage emotionally and with his emotions; Charlie also felt that BDSM has helped understand and give meaning to self-harm and stimming, as there was a greater acknowledgement of the complexity of emotions.

Conclusions

This section further complicated notions of control and pain by unpicking the multiple ways in which participants engaged with and experienced pain, and the wider

discourses of pain, control, and sex, which impacted their lived experience. Firstly, in exploring abjection and how chronic pain is made abject, the thesis demonstrates how people living with chronic pain are pushed to perform self-abjection, to publically and privately reject pain. Pain as an abject idea – and sensation – is thus understood as a bodily fluid, but one that requires expression to become fluid, to become perceived by others. Once others can witness the expression of pain, they too express disgust or horror, both for fear of becoming contaminated with pain, and for fear that in not performing expressions of abjection they might be perceived as *wanting* to become contaminated, of being themselves perverse.

Pain as abject ties into the next section, considering analgesic culture within neoliberal regimes of rehabilitation; pain and the abjected painful body are made part of neoliberalism even as pain and disability are cast as personal failure and personal choice. Within analgesic culture, pain is equated with suffering, and there is an underlying discourse whereby ending pain is desirable as it improves not just the lives of those in pain, but improves society as a whole. For participants, this was experienced particularly in complex relationships with diagnosis, medicine, and care. The complexities of pain were also explored in participants' narratives of care in intimate relationships and friendships, where care sometimes conflicted with expressions of pain, even as care sometimes required those same expressions.

Crippling pain, then, reveals not just how chronic pain presents a challenge to normative constructions of pain, but also reveals how the self is remade with pain, and how self control plays a part in this. Within intimate relationships, BDSM and sex played complex roles in the lives and narratives of participants. For some, BDSM played a significant role in negotiating their social relationships – as well as intimate ones – and their BDSM scenes were important. For other participants, the social aspects of BDSM were less important, but instead their play was about fostering intimacy and sensation. For many participants – regardless of their play style – BDSM was about finding pleasure in uncivilised, abject bodies, and reimagining themselves as people *living* with chronic pain (rather than being *in* pain), and about inviting pain into their experiences of pleasure, as embracing their abjection and disability, their abnormal selves. In doing so, participants’ narratives told of making pain, in ways and places specifically so that their pain could be witnessed, and in ways that could be controlled, tying this into the previous chapter’s exploration of how control of the self, and of pain, played an important part of how participants came to live with their chronic pain.

Finally, this chapter discussed the unexpected ways in which autism, and narratives of being autistic, interacted with narratives of gender, sexuality, and sensation; this is an area I have highlighted as being ripe for further research.

Chapter Eight: Conclusions

This thesis set out to answer the following questions:

- A.** What narratives do people who live with chronic pain and engage in BDSM play tell?
- B.** What do their narratives say about their experience and understanding of pain?
- C.** How can a critically crip reading of these narratives challenge normative conceptions of pain?

In order to do this, I undertook a series of open-ended interviews, supported by diary entries, with eight people who lived with chronic pain and engaged and BDSM play.

In answer to research question one, I found that the narratives were accounts of adjustment, of finding ways to live with chronic pain, and to remake the self. While individual narratives varied, there were several broad common themes:

- The role of time to adjust and then to manage and engage with pain, in order to live with a reliably unreliable bodymind;

- The use of BDSM for pleasure, but also for pain management, for emotional engagement with pain, and to make pain for others to witness, or to control;
- The strain of stigma management, and the impact of being stigmatised and abjected, on their lives;
- The importance of control – through several means – on living with chronic pain
- How pain impacts all aspects of the participants' lives, but particularly their relationships with friends, family, lovers, and care providers.

In answer to question two, their narratives demonstrate participants had wide, complex experiences of pain, and understandings of how they manage pain. Pain was managed using BDSM, as well as more conventional means, but their narratives revealed that management was not always enough, and they also needed space to engage with pain, and to react emotionally to pain without stigma or abjection. Participants showed their experience of pain was impacted by the contexts in which they experienced their pain, but also their previous experiences; these experiences affected their phenomenological selves, and vice versa.

The third research question was answered in a range of ways. Firstly, a critically crip reading of their narratives revealed the discourse of pain as needed control and containment, and as disgusting; the way expressing pain causes people living with chronic pain to be made abject, the object of others' disgust. Their narratives also exposed how pain is assumed to be wholly destructive, but is instead an experience that can be lived with, made a part of the self. Although pain continues to be experienced, and new pain events can be experienced as much worse than chronic pain, people living with chronic pain continue to need a method – or methods – through which they can exert control of their chronic pain, and thus manage their experience of pain.

The participants' narratives also revealed experiences of stigma and being abject which challenge the understanding that speaking of pain is impossible; instead their narratives told a more complex story, where speaking is not always heard, but when it is, that speaking is the cause of becoming abjected, as there are 'proper' ways to speak of pain, which are related to the aforementioned discourse of pain needing containment and control.

Original Contributions to Literature

The thesis makes several original contributions to knowledge. Firstly, it contributes to the work on crip theory by expanding the notion of crip time to reflect the experience of chronic pain, as well as by exploring how understandings of the normal – and ideals of able bodymindedness – are reflected in discourses of chronic pain, and the construction of chronic pain as an abnormal experience, as a disability. The thesis also suggests significant differences between chronic pain and acute pain, and further supports the positioning of chronic pain as a disability.

Contributions are also made to the literature on abjection and stigma in disability, by demonstrating how pain is discursively constructed as a leaky fluid, as contagious or disgusting. Pain thus requires control by the person living with chronic pain – and this ties pain-as-leak into crip theory by giving space to explore how control is necessary for living ‘properly,’ living ‘normally’ under neoliberal regimes. The thesis also demonstrates how control is nonetheless important to living with chronic pain and integrating the experience into the phenomenological self, and thus troubles the notion of pain as always destructive.

The findings of the thesis could be of interest to disability theorists, particularly those interested in chronic illness or crip theory, as well as medical humanities scholars. People living with chronic pain may also be interested. To that end, in addition to academic publication, I shall be seeking to present the thesis in ‘easy read’ form accessible to non-academics and people with learning disabilities.

Implications for Research Practice

This thesis has implications for my own research practice, particularly the need to acknowledge how research alters by affective capacities and sensation²²⁹ – and thus myself. The next section contains reflections on the research practice, I first want to turn to possible areas of research which could be developed following the results of the thesis.

Firstly, the research could support further investigation by disability theorists into the phenomenological experience of crip time, especially in relation to experiences which include fatigue, cognitive impairment, brain fog, and other leaky bodyminds.

²²⁹ See p.352.

Developing crip time in terms of the relationship with policy and practice, as well as rights and citizenship would be particularly fruitful.

Secondly, the research unexpectedly revealed that there is very little research about autistic people with non-normative genders, sexualities, and sexual practices – including BDSM. There is particularly a need for research in this area lead by, or done in partnership with, autistic people.

Thirdly, further research could be conducted in order to explore medical understandings of chronic pain, and medical spaces of chronic pain, from a crip standpoint – in order to interrogate medicine and chronic pain, and also to expose medicine and the medical humanities to crip theory. Having experienced medical humanities conferences on chronic pain, I feel this would be a fruitful conversation for both disability theorists and medical humanities scholars.

Strengths and Weaknesses of the Methodology

This section is a reflective and reflexive critique of the methodology, based off my

own research diary entries during the fieldwork period. Much of it was used in a conference presentation titled *Feel the Pain* (Sheppard, 2015b). In terms of reflection, this section reflects on the reasons for making the initial decisions for how I intended to carry out the research, and how well those reasons were accounted for – whether or not the practicalities of the fieldwork actually worked as planned. In addition, this section reflects on the strengths and weaknesses of the methodology as a whole – in terms of both how it functioned practically, and how well it met the aims of the research.

When it comes to reflexivity, I have taken my cue from the “acknowledgement that the knower and known cannot be separated” (May, 1999, para. 2.1); as a person living with chronic pain myself, I cannot fully separate out my own experience of chronic pain from how I interpret and understand the experiences of others. In particular, my experiences of chronic pain influenced my choice of research aims – and also how I planned the methodology. Thus, there is a need for self-examination in terms of the methods and the concepts which I have employed (Bourdieu, 1993) – as well as an exploration of how the process of research has impacted my self-perception, my own sense of self, acknowledging that the research impacts the researcher just as the researcher impacts the research. The first part of this section reflects on the practicalities of the chosen method as a reflexive exercise; the second part explores

the impact of research on my own experience, and turns to the embodied experience of research.

Practicalities

Choosing to do interviews through multiple communication methods²³⁰ (face-to-face, skype, email, and instant messenger) worked well with this particular group of participants, as it gave a degree of flexibility that a single method alone would not have done. It meant that interviews could be held when participants were unwell, or when we couldn't find time or an accessible space to meet face-to-face. Some participants found being able to talk by Skype enabled them to work with their anxiety, and others found being able to email over several days helped to lessen the energy cost of participating.

Diaries were a secondary focus, and I found that only three of the eight participants kept diaries; this may have been because, as one of the participants explained, the resulting document felt too private to share – but may also have been down to time or energy. However, five of the eight participants completed all three interviews (Edward

²³⁰ See Research Structure on p.182.

withdrew due to the end of a relationship, Michelle due to ill health – only Rita dropped out without contact), and considering the volume of data gathered from those five participants, diaries and interviews for all eight would have given far, far more data than I could have used. The majority of data was collected in the first and second interviews, and the third interview served primarily as a concluding conversation, a time for participants to check in – rather than a data collection interview. If I were to repeat the research, I would consider replacing diaries with emails, or adding another interview between the first and second interview. I would also consider an open-response survey in order to contact other participants – although the change in data collection methods could change the outcomes. A survey, while obviously giving much less detail, could complement interviews in giving a wider range of responses (although this depends on receiving an adequate number of responses to the survey). It could also reach potential participants who felt interviews were too intrusive, or would require too great an energy commitment.

In the interviews, rather than simply recording conversations, I sought to engage my participants in a reflective process in which we explored the meanings of their words together. I attempted to make the research process open and as transparent as possible, explaining both the process, and making their interview transcripts and my

initial analysis notes available to the participants.²³¹ This was informed in part by the ideals of doing emancipatory disability research,²³² but also to ensure that the voices of my participants are kept as authentic as possible (even as I have picked apart the words and assigned new meanings); participants were invited and encouraged to critique my interpretation, to disagree when I placed importance upon a term, and to respond to my readings with their own understandings. I hoped that this would mean my analysis was authentic and true to the experiences of the participants, but also that my participants would feel co-ownership of the research itself. Some participants were more willing to engage in this process, while others preferred to take a step back, and allowed my interpretations to stand; how much involvement participants had was up to them, but I sought to make it clear that I welcomed their involvement and critique.

When participants disagreed with my analysis, I asked for clarification, as well as explaining how I had reached my understanding; sometimes it was a matter of misreading their words, or reading too much from my own perspective, while at other times participants did not understand how I had reached that conclusion. When we

²³¹ See Fig. 2 on p.185 for the timeline.

²³² See p.182.

did not reach an agreement – such as assigning a meaning to a statement, or assigning greater significance – I noted this,²³³ and the participant's understanding was recorded as the 'right' interpretation. This happened relatively few times, but the process of disagreeing was incredibly helpful. Those participants who did engage with this process of critique made a particularly valuable contribution, helping me to understand their experience, and to feel confident in my understanding. I hope – and I feel confident – that they feel my interpretations of their responses are true representations of their experiences.

My own experience with chronic pain gave my participants and I something in common, albeit a rather tenuous something, given that chronic pain accompanies so many diagnoses. I hoped that making my own chronic pain an explicit part of my identity as a researcher, and being open about my experiences with my participants would give us a shared starting point from which I hoped they would view me as a sympathetic listener, a co-experiencer. The reflexive nature of this aspect of the research fitted alongside my attempt to do research with emancipatory aims, to improve the lives of disabled people by furthering understandings of chronic pain – but it also meant that I spent time considering how my identity as a disabled woman and as a person with chronic pain impacted my research in more than practical ways. I

²³³ See p.257 for an example of this.

made my pain a part of the project, in stating that my experience of chronic pain led to the questions I was asking. But in stating that I was a disabled researcher, I made a calculated move, and while the very idea of not revealing my experience with chronic pain struck me from the outset as fundamentally dishonest, I also felt that the same reveal gave me an advantage – a point of assumed sympathy. It at least made it easier to rearrange an interview when my fatigue made it impossible – and it gave rise to moments of shared crip humour when I would forget words in the middle of interviews.

Pain(ful) Reflection

Talking about pain is painful. In seeking to give voice to things that are inexpressible, without reference and without linguistic base (Langdridge, 2007a; Scarry, 1985), we find refuge in metaphor and simile. Explaining chronic pain to people who are not in chronic pain themselves is a tricky business; those of us in chronic pain learn to express our pain in words which we hope will be understood by medics, whom we assume do not share our experience, who have not been in pain for months and years, hoping that when we ask for help we are not assumed to be drug seeking, or exaggerating to get attention, particularly if we happen to present as women, or be

people of colour²³⁴ (Bendelow, 1993; Best, 2007; Nielsen and Fernandez, 2010). In seeking to be understood we become frustrated, upset, disheartened, depressed, and disenfranchised. Aware of this I sought to interview in ways which would acknowledge distress, give space to hopelessness and rage, hoping that my participants desire to explore pain would overcome the desire to avoid it. What I had not counted on was my own pain.

This is not to say I had not planned for my pain; I planned for everything else my impairment throws in my path, and although I could not plan for the dis/ableism of others, I sought to mitigate this experience through organisation, through being a ‘good crip’ who makes up for her limitations. I built extra time into my research timescale, knowing that I would have bad days and flare-ups where I would be unable to do much beyond doze my way through TV programmes (even if I couldn’t predict when). I planned to do interviews by Skype when travel would be too much – or when my participants also struggled with their own energy levels or inaccessible public spaces; I explained to my participants that this was as much about my limitations as their needs. I planned for fatigue, illness, immobility, brain fog²³⁵ (a mental state

²³⁴ See p.106.

²³⁵ See p.260.

where thinking is akin to seeing through fog; you go slowly, and stumble towards words you can only hope are out there) and crip time²³⁶ (Chen, 2014; Kafer, 2013), for all the possible ways in which I would plan to meet the limitations of my body when they contested and conflicted with the demands of being an ideal – *normal* – academic. But I did not plan directly for pain, even though I feel it every day, even though avoiding situations which will cause pain and fatigue has reshaped my life completely and led to the research itself. I did not plan for my pain, because I expected it to be there, sometimes easier, sometimes too serious for numbers on a scale of 1 to 10, worse when it rained in winter, better when I soaked in warm water, but never completely gone.

Pain shaped the questions I started with in interviews; I knew my day to day life influenced my pain, and that my pain did not always feel the same, and so I asked participants how their pain felt, if they could describe their everyday pain compared to the pain they felt during BDSM play scenes.²³⁷ For me, pain often runs hand-in-hand with fatigue, and so in planning for days where I would be too exhausted to function, I was planning to be in pain. Ethically, I was aware of the attitudes of disbelief and

²³⁶ See pp.73, and 231.

²³⁷ See Appendix 2, p.371.

dismissal that often result from talking about chronic pain, especially for women – and especially for women of colour – and therefore I chose to take an attitude of belief, whereby participants' descriptions and identifications were not questioned or queried, and my approach to interviewing was to be sensitive and adapt to the needs of my participants – whether that was including a supportive friend, or changing from a face-to-face interview to a skype on at the last minute, for example. I chose to make my identity as a disabled person explicit, opened myself up to my participants' questions, and shared my experience of chronic pain with them. I reflected on my identity as a person who lives with chronic pain, as a person with a painful body. I did not plan on pain forcing itself into my life because it is already there, because it has forced its way in and sits on my body like malevolent toad on a log.

I did not plan on the discussions I had with participants and on the reflection on their workloads to lead me to a different awareness of my own pain. I am, or rather I was, comfortable with my pain; while not exactly a friend, that malevolent toad is my daily companion, sitting in its corner of my life. After eight years of chronic pain, with minor variations in strength and cause and impact, I thought myself fairly settled into being a person who lives with chronic pain. The fatigue I feel impacted my life, but the changes I was forced to make have become the new routine, and while I might have my moments where I mourn the loss of what I could do, and what I might have

become, I was nonetheless living fairly contentedly, my biggest dissatisfactions not particularly dissimilar to those of my non-disabled friends and colleagues; the cost of rent and utilities, the behaviour of neighbours, commuting, and so on. Some of my dissatisfactions might have been particularly affected by my disability (commuting is particularly hellish when standing for long periods is painful and exhausting), and I was aware of and angry about the issues and problems and dangers facing disabled people – including my friends – but the worst of those were a step removed from my direct experience, and while my anger might stem from sympathy and identification, I am also aware that it comes with a healthy dose of the privileges that come from being who I am. I am as much an ally, a supporter, as I am a disabled person; I can still work, I do not need much in the way of additional support, and I have a small but capable care network of family and friends. In short: I am ok, and I know it.

What I came to realise, however, that was while I had reflected on my pain in terms of practicalities, and it informed my methodology²³⁸ and epistemological approach, I had not reflected on what the pain of others meant to my pain; I assumed that pain is an individual experience, rather than a shared one; I assumed that there would be no sharing of pain, no increase in my pain because I chose to listen to others' narratives of their pain. I did not consider what discussing pain with people who feel pain like me

²³⁸ See p.203.

would mean to how I felt my pain to my own awareness of my pain.

I first noticed it when I realised that while transcribing an interview in which the participant described pushing their pain to the back of their mind in order to ignore it, that I had ignored my own pain that day, that I had not sought to explore it and that I had not reflected upon it (or welcomed it in and sat with it, as my NHS-prescribed mindfulness cognitive behavioural therapy sessions had tried to teach me to do, despite my insistence on falling asleep within moments of thinking about my toes). Instead I had not really paid any attention to it. It is simply there – I have pain in the same way that I have two arms and I take this for granted; pain shapes my phenomenological self, affects how I move through and with the world, but I do not spend much time thinking about how pain shapes my self. In the way that we do not wake up expecting our bodies to have changed radically, I did not wake up expecting to not be in pain. But pain stops you from getting on with things – if I sit and think on it, and on high pain days, my world narrows to just my pain; being in pain can become world-shattering once again, and so living with chronic pain becomes a process of balancing world-shattering with world-remaking. Forcing my pain to the back of my mind, so that it is there but I am forcing my consciousness away from it, this allows me to get on with my day – having my world shattered and remade is exhausting, time-consuming, and (this the part that nobody tells you) boring. It can be lived with only

when we can do more than just exist with it, and this is what people who live with chronic pain learn to do, to have lives around our pain, even if our lives are small and constantly interrupted by pain.

I found that sitting and transcribing interviews about pain – in my specially-ordered specially-adjusted posture-enforcing pain-reducing chair – pushes my own pain to the forefront of my mind. The longer I reflect on my participants' pain, the longer I reflect on my own; each time I address their pain, I address my own – I am forced into painfulness, into consciously being in pain. In sharing our experiences of pain, my participants and I share our pain; listening to narratives of pain is emotional work, pain is an emotional experience (Boddice, 2015) – and as we swap emotion-laden stories, the pain of those stories becomes shared through emotion, shadows of pain passed on through meaning-laden words. I feel my own pain, and I feel a shadow of my participants' pain. The more you speak of pain, the more it can no longer be pushed aside, can no longer be ignored or lived with or existed around. It dominates, it loses meaning – it erases all meaning beyond feeling. It shatters worlds by being the world. Pain becomes all I can see, hear, think, and speak. Pain becomes everything, but the memory of a world beyond, of a world that exists around pain, enables me to push back. I am not willing to let pain become my world; I would rather stitch my world back together, let pain seethe in the cracks, but never more than that.

Pain is not welcome. I do not want to feel my pain – not after spending years perfecting the art of minimising my pain in such a way that I can choose when I feel it. I can choose to engage with my pain, to see the cracks in my world, although sometimes it is not a choice, but for the most part, I can step gingerly over the cracks of pain like a small child refusing to step on the lines between paving slabs. Spending too much time with the cracks lets them widen, lets pain swallow the world, so I want to pull away.

Even as I write this, I feel the push-pull of needing to get away from my pain. Pain is aversive – we seek a way out of it, or we seek a way to justify it. We go to the gym and tell ourselves that there is no gain without pain, and so feeling pain is the sign we're doing the right thing. Pain is justified. It is transitory, a sign of getting better. It is a sign of learning – whether learning to be physically strong, or learning not to touch the pan on the hot stove (Best, 2007; Newmahr, 2011). But it will pass, we tell ourselves. We can even learn to glory in it, while it lasts – pain becomes our trophy. We seek to make pain transitory, to make it pass; it has value only in its transitory state, once it is justified and labelled and reduced to the reasons why we avoid it. When it does not pass – because that is what chronic pain is, pain that is not temporary, that will not pass – we still seek a way out, a way to push it to one side. It is no longer a trophy, it is

a bell we must ring with every step.

This is my way of getting out of it. In reflecting – in forcing my awareness back on my pain, dragging it out into the light and staring it out, I am trying desperately to reclaim my humanity, demonstrating that my pain does not reduce me to the non-verbal, to the animal non-human. I seek to reclaim myself still, to hold my cracked world together. Perhaps as though attacking my pain and pulling it to pieces in search of social meaning, of some idea, will give me the right to wave my pain around and tell others that it is justified because look what I have learned. Look what I have done. I did not want to deal with my pain. Not directly. Not like this. But it forces itself on me – and if pushing it away does not work, maybe letting it in and getting to know it will help.

After giving an earlier – mercifully shorter – version of this section as a paper at a conference (Sheppard, 2015b), a few people told me I was brave. So brave to speak out about it, to go through it all, to be so honest. So brave. I am not brave, I wanted to say (instead of what I did say, what I thought they wanted to hear – thank you, or not at all). I am not brave, because bravery implies I am *overcoming*, that I am here to inspire, that I am acting out inspiration porn for a non-disabled audience (Young, 2012). That my role as a visibly disabled person is to be brave in the face of the

horrors of my ontologically impossible world, whose bravery reminds you of the horrors of failure (because my failure is written on my body), so that my bravery reminds that you must try harder to succeed, because – as the motivational poster reminds us – your excuse is invalid (Kafer, 2012).

I am not brave because I did not speak up to inspire the able-bodied. I did not speak up to inspire disabled people because I do not hold myself as better; I spoke up, just as I write, because navel-gazing introspective reflexivity is important to me, and in putting words on a page perhaps I will open a conversation in how research hurts us, debilitates us. Which is not a call to a debility commons (Goodley, 2014; Puar, 2009), a shared commonality in the face of a collective wounding by the neoliberal academy – although it could be read as such – because I fear that debility flattens out disability, that in showing so effectively how we are all debilitated by neoliberalism it erases our lack of a shared starting point, forgetting that the debilitated self can also be the disabled self, that impairment and limitation and pain is the natural and normal state for some of us, and that state is ok too. That it must be ok, because we have no choice.

Appendix 1: Risk Assessment

In order to gain ethical approval for the research, a risk assessment was carried out as a part of the proposal. The original risk assessment is below:

	Low likelihood	Medium Likelihood	High Likelihood
High Impact	Participants becoming distressed		
	Participants revealing abuse (sexual or otherwise)		
	Issues arising I cannot give advice on		
	Travelling to participant's homes		
Medium Impact		Participants having "difficult" days with variable disability	
Low Impact		travel delays	
		own fibromyalgia flare-up	

Figure 3: Risk assessment matrix for fieldwork

A series of resolutions were also offered:

Issue	Resolution
Participants becoming	Pause or stop interview to enable participants to

<p>distressed during interview, or after interview</p>	<p>recover – ask for permission to continue.</p> <p>Participant may want to discuss distressing issue, and this must be respected.</p> <p>Provide list of therapy services</p>
<p>Participants revealing abuse (sexual or otherwise)</p>	<p>Ask for consent to include in transcript/analysis</p> <p>Ask if participants would like to discuss abuse, or if they would like to pause the interview – react appropriately to distress</p> <p>Provide list of therapy services</p>
<p>Issues arising I cannot give advice on</p>	<p>Ask advice from supervisor, having advised participant that I wish to do so, and gained consent</p> <p>Provide list of therapy services</p>
<p>Travelling to participants' homes</p>	<p>Addresses of participants, and intended travel route and plans, will be copied to supervisor; my partner (who is my usual emergency contact) will have supervisor's contact details.</p> <p>I will take my mobile phone</p>

	<p>If I feel threatened, I will consider my personal safety and react appropriately – whether leaving, calling the police, or simply asking the participant to change their behaviour</p>
<p>Participants having “difficult” days with variable disability</p>	<p>Ask if participants wish to rearrange interview, or use a different method of interview (e.g. Skype instead of face-to-face)</p>
<p>Travel delays</p>	<p>Contact participant, rearrange if necessary</p>
<p>My own fibromyalgia flaring up (i.e. researcher having “difficult” days with variable disability)</p>	<p>Plan ahead – include rest and travel time.</p> <p>If really struggling – rearrange interview or adjust method</p>

Figure 4: table of risks and resolutions, originally written for the ethics clearance

Appendix 2: Call for Participants

The following is the original request for participants, hosted on my blog (Sheppard, 2014a), and shared through social media

I'm looking for 8 – 12 disabled people who use kinky play in their personal lives, to take part in some interviews and keep a bimonthly diary for me over a few months. This will form the research for my PhD.

I am looking at experiences of pain for people who experience chronic pain, but who also receive (or have received) pain as a part of their sex life – from spanking to needle play to flogging, as long as you play with pain, then it counts. What I'm exploring is how we talk about pain, what we mean by pain, and how we understand pain from a social standing. I'm hoping that, in looking at pain from a disability/impairment viewpoint alongside pain that people seek out, I will learn something new about pain, and be able to develop a theory.

If you think talking to me is something you'd like to do, please read on – please pass this on to your friends and acquaintances as well – you never know who might be interested. If you don't want to, or can't, be interviewed, you can still help – by passing this on, tweeting about it, or even forwarding it on to someone.

If you would like to participate – or would like to ask me any questions, please email me at: emma.sheppard@go.edgehill.ac.uk.

About You:

- You must be 18 or over at the time of interview;
- You experience chronic pain – the exact type, or reason, is not important (though we will talk about it);
- You currently, or in the past, have consented to receiving pain as a part of sexual or erotic play (but you don't have to identify as kinky or a BDSMer), and this is something you enjoy;
- You're happy to talk about your experiences of pain, sex, and sexuality;
- You live in the UK.

The Interviews:

Interviews can be held over Skype, by email, or face-to-face – it's about how you're comfortable talking to me, and meeting your accessibility needs (as well as my own).

Face to face interviews will be conducted in a location of your choosing. If you need assistance, please feel free to bring along someone to support you – and let me know if you need any other support, such as an interpreter, or large print copies; I'm disabled myself, so I know how important it is to have what you need in the way of support.

Unfortunately I am not able to pay you for your time. There will almost certainly be cake though.

This is the big commitment – I'm going to want to interview you three times over about a year; for the first six months of that, I'm going to ask you to write a short diary entry twice a month. The first interview will be about an hour in length, and I'll take a short life history, and then ask you some pretty open-ended questions (you can see those below). Then I'll ask you to start keeping the diary entry – written, recorded, however you'd like – twice a month. After six months, we'll talk again, this time for a couple of hours, and we'll go over your diaries and things you said in the first

interview. We'll see where the conversation takes us – I'm interested in your experiences, so there's no answer I want to hear.

Both interviews will be recorded, and I'll then write them up, along with some notes and thoughts about your diaries. I'll ask you to take a look at them, and in our final interview, I'll ask you to reflect on what we've talked about. This is really important, because it gives you a space to tell me your thoughts and what you thought about taking part as well. Last but not least, you'll be able to read over all three transcripts and my initial notes, and tell me if you're happy with what I've got, which is when I go away and write my thesis.

Any information you give me will be made anonymous in any resulting publications – I'll change your name, and try to keep any personal details as vague as possible.

Please get in touch if you have any questions at all! My email address is: emma.sheppard@go.edgehill.ac.uk, or you can get hold of me on twitter, @_ESheppard.

If you'd like to discuss this research with my supervisor, Paul Reynolds at Edge Hill University, he can be contacted at: paul.reynolds@edgehill.ac.uk

The Questions:

The basic questions will be the same for all participants, however, the direction of our conversation will be guided by your answers and what you want to talk about; I might have other questions, depending on what you say. You do not have to answer any question you are uncomfortable with, and I will stop or pause the interview should you wish.

The interview data and transcripts will be made anonymous in the final dissertation, and any other publication resulting from this work.

The following questions will be the initial "starter" questions, although some may not be relevant to you.

- How do you describe your chronic pain?
- How long have you been interested in BDSM? Was receiving pain a part of that from the beginning?

- Do you use pain regularly in your play?
- How does that pain feel?
- Can you compare your chronic pain and your play pain?

The following biographical information will be collected as well:

- Age, gender, sexual orientation, ethnicity
- Impairment/disability
- Age of impairment occurring/developing
- Educational level
- Where you're from
- Do you have/need a carer or personal assistant, if yes, is that person(s) a relative/friend, or an employee?

Appendix 3: Information Sheet for Participants

The following is the information sheet given to all potential participants who contacted me following the call for participants being published. Participants were offered the choice of a standard-size text, large-text, audio recording, or braille translation, as well as translation into another language. None required translation or audio recording.

Title of Study: Kinked and Crippled: disabled BDSM practitioner's experiences and embodiment of pain

Name of researcher: Emma Sheppard

Telephone: 07809833787

Email: Emma.Sheppard@go.edgehill.ac.uk

About the Research

The study is being done as part of my PhD at Edge Hill University.

This study wants to explore the experience of chronic pain and sexual/erotic pain – I want to explore the relationship between them, and how we talk about both experiences. What I’m exploring is how we talk about pain, what we mean by pain, and how we understand pain from a social standing. I’m hoping that, in looking at pain from a disability/impairment viewpoint alongside pain that people seek out, I will learn something new about pain, and be able to develop a theory. This may also have a small impact on how chronic pain is treated, or how BDSM is understood – please ask if you want to know more about the details.

Your access needs will be respected – please let me know if you require a BSL interpreter, large print or digital copies of anything. You are welcome to have a carer or personal assistant present for the interview; they will also need to sign a consent form. If you have any other needs, please let me know.

The Process

If you agree to participate, we’ll agree a mutually-convenient time to meet face-to-face, in a location of your choosing, or we’ll talk over Skype or email. The first interview will take an hour or so, and I’ll ask you to keep a bi-monthly diary for six months, until we meet again, for a two-hour interview. I will write up transcripts of

those two interviews, along with my thoughts, and you will be asked to reflect on your experiences in a final interview, which will take about an hour. I will be writing my own research diary, and you will be able to see any parts of it relating to you or the study as a whole – you just have to ask. I'll be asking you to approve your transcripts and my initial notes, at the six-month and final interviews, but you can see them at any point.

This whole process will take approximately one year to eighteen months to complete.

The interviews and diary writing are not intended to be distressing (although I know we'll be discussing sensitive topics), so if you feel yourself becoming upset, please let me know – we can always stop the interview, or simply take a break. Once we've started, you are free to stop at any time, for any reason. Please do let me know if you are upset or distressed, or are having any problems – at any point. We'll discuss your feelings and you can decide how to move forward. However, I'm not a trained counsellor (I'm a social scientist) – so I've made a list of BDSM-friendly counsellors and therapists for you to talk to if you want to seek them out.

The Questions

The basic questions will be the same for all participants, however, the direction of our conversation will be guided by your answers and what you want to talk about; I might have other questions, depending on what you say. You do not have to answer any question you are uncomfortable with, and I will stop or pause the interview should you wish.

The following questions will be the initial “starter” questions, although some may not be relevant to you.

- How do you describe your chronic pain?
- How long have you been interested in BDSM? Was receiving pain a part of that from the beginning?
- Do you use pain regularly in your play?
- How does that pain feel?
- Can you compare your chronic pain and your play pain?

The following biographical information will be collected as well:

- Age, gender, sexual orientation, ethnicity
- Impairment/disability
- Age of impairment occurring/developing

- Educational level
- Where you're from
- Do you have/need a carer or personal assistant, if yes, is that person(s) a relative/friend, or an employee?

Consent, Confidentiality, and Anonymity

Before the first interview takes place, you will be asked to sign an Informed Consent Form; the interview will not go ahead until you have signed it. Electronic copies will be available if the interview is done via Skype or email. If you have any questions about the forms, this information sheet, or the study, please do ask me.

The interviews will be recorded, and then transcribed. I may pay another person (who is experienced with transcribing these sort of interviews, and who I trust completely) to help me with the transcription – you can ask me to transcribe the interview myself if you'd prefer. Your information will remain anonymous, and transcripts and recording files will be kept in secure locations (password-protected for digital copies, in a locked box in my own home for paper copies)

The contents of all three interviews, and the diaries, will remain confidential – only myself, my supervisor Paul, and the transcriptionist will ever see complete copies. Only I will ever have complete access to everything at all times. When it comes to writing up, I will make your details as anonymous as possible (you're welcome to choose your own nickname).

You will be able to withdraw from this process at any point, and I will remove any parts of the interview or diary you're not happy with me writing about. However, there will be a cut-off point – six months after the final diary. This is because, following the end of the research process, I will be writing up for publication, and once it goes past this stage, it would be impossible for me to fully remove everything.

The analysis of our interview will be written up in my thesis, and there may be other publications or conference talks as well. If you'd like to see these finished pieces, please let me know, and I'll happily send you a copy.

The study is supervised by Paul Reynolds, who may be contacted at the email address below.

Please keep a copy of this sheet, and the consent forms, for your records. Please do not hesitate to get in touch with me at any time.

Contact Details

Emma Sheppard (researcher) – Emma.Sheppard@go.edgehill.ac.uk or 07809833787

Paul Reynolds (supervisor) – Paul.Reynolds@edgehill.ac.uk

Appendix 4: Consent Sheet for Participants

The following is the consent form given to participants, at the same time as the information sheet. Some participants signed the consent form electronically, some preferred a printed version. Participants were given a copy of the consent form to keep. Participants were offered the choice of a standard-size text, large-text, audio recording, or braille translation, as well as translation into another language. None required translation or audio recording.

Title of Study: *Kinked and Crippled: experiences and embodiments of pain*

Researcher: *Emma Sheppard*

- ☐ I have been informed about the nature of this study and willingly consent to take part in it.
- ☐ I have read and understood the information sheet.
- ☐ I agree to take part in three interviews (which will be recorded) and to keep a diary, which I will give to the researcher at the end of six months
- ☐ I understand that the content of the interviews and diary will be kept confidential, and any direct quotes or information used will be made anonymous

☐ I understand that I may withdraw from the study at any time during the next eighteen months, and that I can ask for parts of my data to be removed.

☐ I understand that I have six months after the final interview, at which point I will be no longer able to remove any data.

☐ I do / do not [delete as appropriate] give consent for the researcher to use the services of another to transcribe our interview recordings.

☐ I am over 18 years of age.

Name _____

Signed _____

Date _____

There should be two signed copies, one for the participant, one for the researcher.

Appendix 5: Diary Suggestions

The following was given to participants at the end of the first interview.

This diary is not intended as a daily record of events, and what you write (or record) is up to you. If possible, please make an entry every couple of weeks, although you are free to write more frequently if you wish – entries don't have to be regular. It would be particularly helpful if you could make an entry after play events, or when you feel your experiences are significant because of your pain. If you're not sure what to write/record, these prompts may help you:

- If you're writing about a significant event or experience:
 - Describe what happened – who you were with, where, what did you do?
 - How did it make you feel, emotionally and physically?
 - Why was the event/experience significant to you?
 - Describe your pain – perhaps over time during the event, or before and afterwards.
- If you're writing more generally
 - How have you felt over the last week or so?

- Has anything happened that made you feel particularly strong emotions? Positive emotions included!
- Describe your physical state – perhaps over the last few days, or just as it is right now.
- Have you played recently? What did you do? What would you like to do?
- Other ideas
 - Recounting past experiences with pain – can you remember the first time you explicitly set out to play with pain? Or memorable events that included pain?
 - How you feel about taking part in the research? Why did you want to take part? What would you do differently?
 - Any books, films, twitter posts etc. that have resonated with you? Why?

Please try to write a couple of paragraphs, but only as much as you want to – and please write more if you'd like.

If you're not sure what to write about, or you have any questions, please don't hesitate to get in touch with me – either by email on emma.sheppard@go.edgehill.ac.uk or give me a call over Skype.

Appendix 6: Information Sheet and Consent form for Personal Assistants, Carers, and Interpreters

The following was prepared for personal assistants or carers (or friends), as well as interpreters, that the participant wished to have present during the interview.

Information Sheet for Interpreters and Assistants

The interview you'll be present in is part of a research project for my PhD. I'll be looking at experiences of chronic pain and sexual/erotic pain, so the content of the interviews will be sexually explicit, and may discuss practices you disagree with. We may discuss what could be considered graphic violence and dangerous practices.

As a result, I'm asking you to give consent to being present – I don't want anyone to feel uncomfortable. I'm happy to talk over the research beforehand, and can point you towards some resources that will explain the topics if you'd prefer to do your own reading.

If you're attending as an assistant, you will know the person you're coming to help – and while you're welcome to discuss the content of the interviews with them, I would ask that you respect both their privacy and confidentiality – the contents of this interview will be anonymised before anybody else reads about them, and the participants may not want other people to know what they've been talking about.

If you're attending as an interpreter, you might know the person you're interpreting for, but you might not. The principle of confidentiality still stands, though – please don't talk about details of the interviews with anyone except the participant or myself.

The interview will be recorded and then transcribed.

If you have any questions, please let me know – it's important to me that you're comfortable taking part.

Consent form for Interpreter, Carer or Personal Assistant

Title of Study: Kinked and Crippled: experiences and embodiments of pain

Researcher: Emma Sheppard

☐ I have been informed about the nature of this study and willingly consent to be present during the interview in order to provide Sign Language translation services / care or assistance as requested by the participant [delete as appropriate].

☐ I understand that the content of the interview will be kept confidential.

☐ I will respect the confidentiality of my employer and the research, and not discuss the interview once it is complete, except with my employer.

☐ I am over 18 years of age.

Name _____

Signed _____

Date _____

There should be two signed copies, one for the interpreter/carer/assistant, and one for the researcher.

Appendix 7: Transcript and Diary Samples

Diary Entry, Julie

3/6

Whilst I haven't had chance to indulge in much kink-with-others-in-person (in fact over a month), I've had a few phone encounters. Inflicting pain on myself is a weird thing...

Anyway, inflicting pain on my body at someone else's instruction and hearing their response works. It has that interaction with someone else. That validation of the pain. Their response to the sharp intakes of breath, the small moans, you can recognise the smile in their voice.

People don't see my chronic pain. I avoid admitting the levels it is at. For fear of some level of bad response. Because the "aww, I'm sorry" frustrates me, the "you must be weak" hurts me, and the "stop complaining" breaks me. So I don't accept it at some level, I certainly don't project it outwards unless I have to. So nobody validates that chronic pain. Out of my own choice and so they just see me and don't ask questions.

So that response from another, that validation of "oo, that hurts, doesn't it?" with a grin, even over the phone, embraces the pain into a more positive, pleasure filled place.

First Interview, David

This interview was conducted over Skype and then transcribed.

Interviewer: mm, no, I know – it's a real struggle sometimes. I admit I walk, but because I have the dogs I don't have the choice. Um, but if I didn't, I probably would quite happily not leave the house, because – it hurts. And doing things makes it hurt more. Ok, my next question – how long have you been interested in kink? BDSM? What's your preferred term for it, by the way?

David: tends to be kink because that's a bit more *flexible*.

Interviewer: yep, ok

David: um. BDSM is part of that, but kink kind of covers [sighs], uh, queer stuff, odd head stuff – things that aren't necessarily in that little BDSM box

Interviewer: yeah. Ok. We'll go with that. Yeah, how long have you been interested in kink?

David: uh – kind of aware of [pauses] to a certain extent as long as I can remember, just, little things like picking scabs deliberately and, I don't know – supergluing my fingers together to restrain my hands and little things like that. But actually discovering it was a thing and it was something people actually talked about, and did, um – must have been when I was back at uni, so, sort of, um, 20, 21-ish

Interviewer: yep. Um, and – so you said restraining your hands, was pain a part of that from the beginning?

David: uh, not – uh, to a certain extent it just, uh, not being able to fidget without a certain degree of resistance, which is kind of awkward, because when you need to fidget and move, and you can't – it almost aches

Interviewer: mm

David: um [pauses]

Interviewer: and then, ok – so in [David interrupts]

David: so as – that it was something, something I was aware of, but also something I'd not considered playing with, for want of a better term, um – I was aware that, say if I'd come off me bike and I was picking gravel out of me knee, I found that sensation

interesting, but I – it hadn't occurred to me as something that could be done deliberately – does that makes sense?

Interviewer: yeah, that makes sense

David: um, so kink is – in a lot of ways it's about exploring that vocabulary in a – safer, healthier way?

Interviewer: mm-hmm. Yep. What - do you have any particular, when it comes to kink what are your – do you have particular interests, directions?

David: um [pauses]. Uh – to a certain extent, yeah. Some aspects of edge play. Um – this is kind of a bit weird because as much as anything, most of my experience has really been as a top, rather than a bottom. But I, um [pauses] certainly, where there has been more of the bottom end of, it's been – I guess it comes under primal play. So lots of biting, lots of scratching and – play fighting, almost

Interviewer: yep. Um – and – would you say you're more of a top, or has it changed?

David: uh – I've [sighs] my masochistic streak has always been a thing – I, I got introduced to kink almost as a way out of self-harming, sort of – friends were aware I was cutting, um – not so much in a self-destructive way, or – but as a way of self-stimulating.

Interviewer: yeah

David: and, um – so, I sort of, that got picked up on, and sort of, “this is a thing, do you know about this?”, and I – I ended up, a load of us going to the [large event], um – sort of, I was vaguely aware of the scene but at the same time, sort of out of the loop a bit, so it’s only really when I came back to [home town] in 2000 that I found out about the local munch and I actually started going to local events and stuff. So it must have been about 2002.

Interviewer: mm-hm. And would you say you’re active now, on the local scene, or is it?

David: Fairly active. I go to a lot of munches. There’s a couple of clubs and events that it’s – I go to when I can, but as to a certain extent it’s sort of limited by finance and, uh – and what’s around [the local area].

[section removed for anonymity]

David: yeah, so I was sort of going along to [former rope] and starting to get my head around rope as a – not so much, yes, rope can be pretty and yes, rope can be interesting, but it’s also – can be intimate and interactive – and sort of starting to get my head around that and starting to get the point of that a bit more

Interviewer: yep

David: but then that sort of blew up and, yeah, sort of

Interviewer: the scene hasn’t been quite so active?

David: it blew up quite big, from that, and it's, its cut back. There's still a couple of local clubs, um, because my main transport is the motorbike, sort of going to a play event, sort of out in the sticks and having to try and get back on the bike – not so good

Interviewer: yeah, it can be a little bit

David: yeah, so, not so much as I'd like, but. Yeah.

Interview 2, Charlie

This interview was conducted face-to-face and then transcribed.

Charlie: Yeah. Well, it's about control again, isn't it? This idea of we're supposed to be in control.

Interviewer: Yeah, and I think sometimes pain as well is almost a bodily fluid in that sense.

Charlie: Yeah, I think so. Yeah. Something you can't control and it just sort of spills out.

Interviewer: Yeah. So a space for it to spill out is sometimes...

Charlie: ... useful...

Interviewer: Yeah.

Charlie: ... and welcome and wanted. Sought out.

Interviewer: Yeah. And it's kind of... Yeah, that's one of the other ideas that I'm...

Charlie: Doesn't necessarily impact on people in the sense that you're not going to piss on somebody's seat with your pain, but... so it's slightly different, but... So in some ways, there's even less scope for it to spill out, because people don't see it when it does.

Interviewer: But also when you're in a space where expression of pain is allowed, if not indeed encouraged, you know, it's... they're more welcoming to hear it.

Charlie: Yeah, yeah. You're able to talk about it.

Interviewer: Or they're not as discomfited by it, because... But I mean there's also the assumption that the pain that people are expressing in that space is, particularly when it comes to kink, is a pain that they are... not enjoying but complicit with.

Charlie: At least complicit with? Yeah.

Interviewer: That there is a certain level of having sought it out, on some...

Charlie: Yeah.

Interviewer: So it's... it's safer as well in that sense, but it's still somewhere you can express.

Charlie: Is there a...? Have you come across, like, any...? Oh, I've lost my train... It started somewhere with what you were saying about the gendered kind of bias around some of this, because there's a lot of things about women's bodies that they're not supposed to talk about. There's a few that men aren't supposed to talk about, about their bodies, but somehow they get to talk about it more with each other, I think, in a... even if it's in a joking kind of... hierarchical kind of way maybe. But particularly when you're talking about containment and leaking and stuff, and, you know, just with things like menstruation, that's an uncontrollable event that happens regularly in every woman's life. Well, most... many... most women's lives, not every. Most women's lives. And they're not supposed to talk about it really.

Interviewer: Unless they're with...

Charlie: Other women.

Interviewer: ... other women. [00.30.00] Of the same age, assumed experience.

Charlie: Yeah. Peer group of some sort.

Interviewer: Yeah. I mean, I would say... But, yes, it is very gendered, basically.

Charlie: Yeah, I was thinking in terms of the wider sort of narrative around control and leakiness and stuff.

Interviewer: Yeah, it's...

Charlie: Because things like childbirth, and continence around childbirth and all that sort of stuff, there's going to be a...

Interviewer: Yeah, it's quite... it's quite heavily gendered in that sense. There's quite a lot around, yeah, women's... and part of the reason that women... one of the kind of discussions that comes up is this idea that part of the reason that women are lesser, blah blah blah blah, is because of their leakiness.

Charlie: Because they're not in control.

Interviewer: Yeah, because it's assumed...

Charlie: And it's always that whole thing about being in control of your emotions or not, again, isn't it? There's bodily control, emotional control, even if it's just a different way of expressing your emotions but it's not the male-dominant way, and so, yeah...

Interviewer: Yeah, and this rejection of a certain way of doing something.

Charlie: Yeah. So you've got the norms that are set up for both physical control and emotional expression, and women don't fit those and so are considered failing against those norms when they're just, you know, male supremacist norms or something.

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